Contemplating the Future with Chronic Fatigue Syndrome: A Grounded Theory Exploration of the Experience of Self and Contemplation of the Future among Individuals with Chronic Fatigue Syndrome

Volume 1: Academic and Research Dossier, plus summary of Clinical Experience.

by

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I would like to thank all my clinical, academic and research supervisors for their contribution and dedication in my training as a clinical psychologist.

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INTRODUCTION TO THE PORTFOLIO

The portfolio is a compilation of the academic, clinical and research work completed for the Doctorate in Psychology Course in Clinical Psychology (PsychD) for the University of Surrey. The portfolio aims to highlight the depth and range of experience and development in competencies gained across the three years of training. The portfolio comprises two separate volumes, as described below.

Volume 1
This volume contains the academic dossier of the PsychD course portfolio, comprising of: two essays; three Problem Based Learning reflective accounts and the summaries of two Case Discussion Group Process accounts. The portfolio also contains the research dossier comprising: the Service Related Research Project; a summary of the Qualitative Research Project completed in year two; the Major Research Project and the research checklist, which summarises research experiences gained across the three years of training. The final part of this volume comprises the clinical dossier which contains brief overviews of the placements undertaken and subsequent clinical experiences gained alongside a summary of each of the five case reports completed across the training course.

Volume 2
This volume comprises the full clinical dossier and is split into two parts, each part comprising of two sections, the content of which are explained at the outset of each. Part 1 includes all five placement contracts, supervisor end of placement evaluation forms (alongside the mid-placement evaluation form from year 1), clinical logbooks and trainee evaluations of the clinical placement. Part 2 comprises all five case reports completed across the training course, alongside the two full case discussion process accounts.
ACADEMIC DOSSIER

This section of the portfolio contains two essays which critically examine a range of psychological issues (both concerning practical and theoretical dilemmas) associated with clinical psychology, in relation to the contexts of adult mental health and wider professional issues. The portfolio also contains three Problem Based Learning reflective accounts and summaries of the two Case Discussion Group Process accounts.

Any reference to current/previous clinical work has been anonymised throughout academic assignments.
ADULT MENTAL HEALTH ESSAY

"To what extent is membership of an Ethnic Minority Group (in the UK) influential in the process of diagnosis and treatment of depression?"

Year 1: January 2005
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To What Extent is Membership of an Ethnic Minority Group (in the UK) Influential in the Diagnosis and Treatment of Depression
INTRODUCTION

This essay will explore how membership of an ethnic minority group, within the United Kingdom (UK), influences the diagnosis and treatment of depression. Britain’s ethnic population is at around 4.6 million and increasing (Government Census 2001). Government guidelines stipulate that effective mental health care should be accessible for all, irrespective of ethnicity (National Service Frameworks, Department of Health, 1999).

As definitions of both ‘ethnicity’ and ‘minority populations’ vary, for the purpose of clarity, the term ‘ethnic minority population’ will refer to members of any group sharing race, cultural/religious values or generational traditions, where members have less power over their lives, or are represented in smaller numbers than members of the majority group. This definition reflects the complexity associated with definitions of both ethnicity and minority groups, integrating Fernando’s (1990) concept of ethnicity with Moghaddam and Studer’s (1997) concept of minority populations.

Although focussing on depression, it is not within the scope of the essay to provide detailed accounts of various diagnostic and treatment approaches. However, a brief overview of western approaches to diagnosis and treatment of depression in Britain enables an understanding of how membership of ethnic minority populations influences these processes. As I am currently learning about cognitive approaches to the treatment of depression within my placement, focussing on this orientation throughout the essay will benefit my learning.

Following this overview, the prevalence of depression and service utilisation among ethnic minority populations in the UK will be summarised, setting the context for the essay question.

I will then explore socio-cultural differences pertinent to the diagnosis and treatment of depression across ethnic populations including language barriers, socio-economic factors, stigmatising beliefs, cultural orientation, cultural representations of depression and issues within the therapeutic relationship, highlighting diagnosis and treatment issues throughout. The essay aims to provide a detailed account of selected issues; it is recognised that there are issues surrounding the migration process (e.g. pre-immigration trauma) that are not discussed, as focussing on theoretical issues pertinent across all ethnic minority populations (migrants and non migrants) will apply to wider settings.
Finally, I will summarise the diagnosis and treatment issues raised, providing recommendations for effective service provision.

Throughout the essay, I have predominantly used British research. Where this was not possible, literature from elsewhere has been used, as the pertinent theoretical issues from these papers apply to the UK.

Although my clinical experience working with both depression and members of ethnic populations is limited, throughout the essay I shall reflect upon my clinical experiences (gained whilst an Assistant Psychologist) with a Muslim girl (Samira\(^1\)) and her family.

15-year-old Samira presented to the team with recurrent and persistent headaches (with no apparent organic cause) that were concerning and distressing both Samira and her family. As it was felt that distress, produced by the focus on academic success within the family and Samira’s isolation from her friends, were underlying her physical symptoms, the team\(^2\) attempted to work with Samira and her mother to reduce this pressure by encouraging Samira to undertake age-appropriate activities with friends. Unfortunately, both Samira and her mother found this approach challenging and after two further sessions, ceased engaging with the service.

Whilst not specific to depression, this case left me with unanswered questions and reservations regarding the ability of mental health services to work effectively with members of ethnic minority groups. Reflecting on these experiences has increased my understanding of the theoretical issues and their implications for my clinical practice.

**DEFINITIONS, DIAGNOSIS AND TREATMENT OF DEPRESSION WITHIN THE UK**

Two formal psychiatric classification systems aid the diagnosis of depression: American Diagnostic Statistical Manual (DSM-IV); European International Classification of Diseases (ICD-10). These typically define a clinically significant depressive episode as the co-occurrence of low mood (persisting over a 2-week period) with a variety of physiological, behavioural, cognitive and emotional symptoms, including: pervasive and persistent patterns

\(^1\) Name changed to preserve anonymity.

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of negative thinking, feelings of hopelessness and various somatic symptoms i.e. disturbed sleep and reduced energy/appetite (Gotlib & Hammen, 1997).

Although many Clinical Psychologists within the UK feel uncomfortable using this ‘medical’, potentially stigmatising, approach to the assessment of depression, the biological, behavioural, cognitive and emotional elements are often still utilised, albeit less formally.

Increases in distorted patterns of self-critical thinking, feelings of hopelessness, reduced self-efficacy (capacity to deal with challenges to achieve personal goals) and subsequent suicidal ideation, are universal cognitive markers of depression. Intervention emphasises the identification and challenging of the client’s negative thoughts about themselves, the world and the future, in order to reduce feelings of hopelessness and increase self-efficacy. Other elements may include activity scheduling and assertiveness training (where lack of assertiveness is maintaining depression, Beck, 1979).

DIFFERENCES IN THE EPIDEMIOLOGY OF DEPRESSION AMONG ETHNIC MINORITY GROUPS

Prevalence
The prevalence of depression among ethnic minority groups living in England and Wales is mixed. Generally, with the exception of Pakistani women (Nazroo, 1997, Bhui et al, 2004) females from all ethnic groups exhibited higher rates of depressive symptomatology than men, with increased rates observed in migrant populations (Nazroo, 1997).

Regardless of gender, members of white minority/Caribbean populations showed higher levels of depressive symptomatology/suicidal thoughts compared with native white British populations (Nazroo, 1997, Shaw et al, 1999).

Conversely, members of predominately-Asian groups presented with lower levels of depressive symptomatology (Nazroo, 1997). In contradiction with the apparent lower overall rates of illness among South Asians, analysis of suicide mortality figures revealed higher rates among Asian women compared with members of other ethnic groups (Bhugra et al, 1999, cited in Bhugra & Desai, 2002).

Service Utilisation
Despite accessing help through general practitioner settings to the same extent (Shaw, 1999) and in some cases more often than white majority groups (Gillam, 1989), research suggests...
that members of Indian-Asian, Southern Irish, West Indian (Gillam, 1989) and Caribbean (Nazroo, 1997) populations are less likely than whites to consult their GP for depression. Conversely, the relationship between depressive symptomatology and the utilisation of professional services/medication for Indian/ African-Asians is similar to white majority populations.

SOCIO-CULTURAL FACTORS ASSOCIATED WITH DEPRESSION IN ETHNIC MINORITY GROUPS

Socio-Economic Context of Ethnic Minority Populations
Understanding the wider social context facing ethnic minority populations in the UK is necessary when attempting to understand the experience of depression within these populations. Research suggests that members of African-Caribbean populations, within the UK, earn less than their white counterparts. Furthermore, members of all ethnic minority groups are more likely to be unemployed, live in areas of lower social class/inferior housing and experience discrimination and racial harassment (Modood et al, 1997).

These socio-economic disadvantages, combined with experiences of repeated discrimination, are likely to place these individuals under continuing stress, which according to social theories of depression, increases vulnerability to depression through reducing self-esteem (Brown & Harris, 1978). Consistent with this, variation in depressive symptomatology across all ethnic groups, is associated with socio-economic factors (Nazroo, 1997); furthermore, self-esteem has been observed to mediate the relationship between discrimination and depression among Asian-American males (Howe & Warden, 2004).

Exploration of socio-economic difficulties is important in understanding factors maintaining depression through their impact on the self-esteem of ethnic minority populations. This is pertinent, as Husain et al (1997) found that Pakistani populations (in the UK) willingly discussed social difficulties, whilst psychological indicators of depression were rarely reported.

Language Barriers
Language barriers between client and clinician will limit detection of depression by GPs/physicians. Consistent with this, Nazroo (1997) observed associations between English language proficiency and increased depressive symptomatology among South Asian populations in the UK, arguing these findings reflect increasing abilities to express...
psychological distress by those more fluent in English. Language barriers between client and clinician will thus limit the clinician’s ability to gain a full understanding of the extent of the client’s depressive symptoms.

**Differences in the Experience of Distress**

Diagnostic difficulties are further compounded by differences in the symptomatic expression of distress across ethnic populations. Consistent with this, research identifies increased physical (somatic) presentations of depression in African-American (Brown *et al.*, 2003) and Asian-Canadian populations (Raguram, *et al* 1996).

Furthermore, research has suggested that *cognitive* expressions of distress differ within these populations. Studies of the Beck Depression Inventory (psychometric test assessing physiological, affective, cognitive and motivational indicators of depression, Beck *et al.*, 1961) observed increased endorsement of affective-somatic and self-critical markers of depression as opposed to indicators of depressed mood, in African-American women (Williams & Wilkins, 2004). Research also observes a weaker relationship between self-efficacy and depressive symptomatology among Chinese students in Japan (Stewart *et al.*, 2003) and reduced self-enhancing (viewing the self more positively than the normative criterion) tendencies among Asian-Canadian populations (Norasakkunkit & Kalick, 1990).

Before discussing diagnostic and treatment issues raised by these findings, it is necessary to understand further the socio-cultural factors underlying them, including the presence of stigma and differences in cultural orientations/representations of depression.

**Stigma Surrounding Depression**

Theories of stigma, not specific to ethnic populations, distinguish between self-stigma, occurring where cultural attitudes toward mental illness are steeped in negative images, thus reducing self-esteem and public stigma, where mentally ill individuals are discriminated against and robbed, by the wider society, of important opportunities e.g. employment, housing. (Corrigan, 2004)

Beliefs that mental illness is incurable and public stigma surrounding the negative impact of mental illness on reducing arranged marriage prospects are documented forms of stigma within Asian-Canadian populations (Raguram *et al.*, 1996).
Diagnostic and treatment issues
Research suggests that stigma associated with mental illness affects the expression of depressive symptoms among ethnic populations. Somatic symptoms resemble common illness experiences within society that are less stigmatising than psychological expressions of distress (Raguram et al., 1996). Consistent with this stigmatising beliefs toward depression are associated with physical, as opposed to psychological, expressions of distress among Asian-Canadian populations (Raguram et al., 1996).

Where stigma limits the expression of suicidal thoughts/feelings of hopelessness, the clinician’s ability to accurately diagnose depression and assess the risk of self-harm is limited. This is particularly relevant, as research suggests somatic presentations of distress are prevalent among Asian cultures, where the suicide mortality rate is notably high (Bhugra et al., 1999, in Bhugra & Desai, 2002).

Although stigma toward mental illness has been documented throughout society, regardless of ethnicity (Corrigan, 2004), I would argue that the socio-economic difficulties facing members of ethnic minority populations suffering with depression heighten the potential consequences of public stigma. For them, seeking professional help may be perceived as synonymous with increasing discrimination/withdrawal of advantages from the wider society. It is possible, that for members of ethnic groups already facing socio-economic hardship and discrimination, the cost of attending therapy (in terms of further self and public stigma) might seem to outweigh the gain, reducing motivation to seek help/engage in treatment.

Reflecting upon my experience with Samira further increased my understanding of these issues.

At assessment, concerns that Samira might be labelled ‘mad’ were voiced by both Samira and her mother. However, the team did not acknowledge cultural frameworks of understanding underlying these fears and anxieties. It is possible that visiting the mental health team had been difficult for Samira and her mother due to a fear of Samira being stigmatised. Explorations of family/community reactions to their visits to the team, through acknowledging these difficulties, could have enabled sensitive attempts to engage with the family.

Differences in Cultural Representations of Illness
Whilst stigma and language barriers undoubtedly exacerbate differences diagnosing and treating depression, reported difficulties translating western psychiatric concepts (including
depression) into other languages (Nazroo, 1997), suggest that concepts used within western psychiatry may lack meaning for ethnic minority groups.

Explanatory models are methods by which individuals understand and interpret mental/physical illness. Research suggests that models held by Eastern and Western philosophies differ; the dualistic, mind-body distinction common within the western world appears to lack meaning in eastern cultures. Rather, the mind is viewed as a continuation of the body, representing a more ‘holistic’ framework for understanding illness (Fernando, 1990) where depression may be conceptualised in Humoral terms, pertaining to imbalances between hot and cold states within the body (Bhui et al, 2004).

Alternative theories conceptualise depression as the product of some external spiritual, magical or religious agency such as damnation, the ‘evil eye’, spirit possession (Fernando, 1990) and divine retribution (Dein & Sembhi et al, 2004).

Furthermore, in some cultures, the cause of depression does not lie within the individual; rather it is a normal reaction to social or moral stressors. Consistent with this, tendencies to understand depression as the expected result of these stressors, with a particular emphasis on conflicts occurring within the family, have been documented within South Asian-American (Karasz, 2004) and African-American women in the US (Brown et al, 2003).

Cultural Orientation
Before discussing the diagnostic issues raised by the above, it should be noted that differences in depressive experiences may be further influenced by differing concepts of ‘self’. Western ‘independent’ construals conceive the self as independent of groups with a goal to become independent from others by expressing one’s unique abilities. By contrast, non-western cultures perceive the self as ‘interdependent’. Emphasis is on connectivity with others and maintaining interdependence by valuing and achieving the goals of the wider group (Markus & Kitayama, 1991). Group, as opposed to personal, identity defines the self. Whilst failure is stigmatised, conformity, academic/economic success (Bhugra & Desai, 2001) and traditional gender roles – for women this may include caring for one’s children and family - are also highly esteemed.

Cognitive theory would argue that reduced self-efficacy and distorted patterns of self-critical thinking maintain depression. However, research suggests the relationship between these factors and psychological wellbeing differs in interdependent cultures. Specifically it is

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argued that self-enhancement serves no useful function for the interdependent self, which by contrast, employs self-criticism as a form of subordination to group standards (Harrington & Lui, 2002). Consistent with this reduced self-enhancing tendencies are observed in Asian-American populations, accounting for significant variance in depressive symptomatology (Norasakkunit & Kalick, 2002).

Furthermore, the concept of self-efficacy within interdependent cultures has also been questioned, as members of interdependent cultures are believed to gain fulfilment through relying on others to achieve group, as opposed to personal, goals (Stewart et al, 2000).

Diagnostic issues
Instruments used to aid diagnosis, e.g. DSM-IV/ICD-10, emphasise the universality of the physiological and psychological aspects of depression (cognitions, affective/motivational disturbances) regardless of culture. This represents an ethnocentric ‘racist’ tendency among western clinicians to view reality from their own cultural experience and perspective. This results in the traditions, behaviours and practices of other cultures being considered as strange, or deviant (Klienman, 1987).

The differing relationship between psychological wellbeing and cognitions of self-enhancement/self-efficacy among interdependent cultures could subsequently lead to an apparent absence of these familiar western cognitive markers of depression within the diagnostic process. Similarly, where depression is conceptualised as the normal reaction to situational stressors, or where somatic presentations are understood as the natural product of imbalances in Humoral states, psychological aspects of depression may be deemed less significant and thus not reported.

However, rather than reflecting the purely physical experience of depression, these findings may reflect cultural differences from western cognitive understandings of depression. Cross-cultural research into self-enhancement and self-efficacy tends to rely on western measures of both these factors and depression itself. Other research argues that western indicators of depression and self-enhancement have different meanings within interdependent cultures and are expressed in different ways, e.g. through maintaining interpersonal harmony within the group, as opposed to the achievement of personal goals (Markus, 1991). Furthermore, cultural demands for self-restraint and modesty (necessary for group acceptance), may limit the expression of self-enhancing tendencies in favour of self-criticism (Kurman, 2003).

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Subsequently, where clinician’s attempt to evaluate symptom clusters of non-western populations against western standards of normality, diagnostic difficulties are likely to occur. This phenomenon is termed the ‘category fallacy’, whereby the use of research or treatment developed in a particular culture fails to identify the same issues in a different group, because they lack meaning (Klienman, 1987).

Ultimately, failure to acknowledge differences in depressive experience across cultures could limit the recognition of depressive symptomatology and subsequent risk of self-harm within ethnic minority populations. Further difficulties may arise as the natural self-critical tendencies of ‘interdependent cultures’ may be falsely attributed to depression, leading to an inappropriate targeting of unnecessary therapy. Consistent with this, both ‘somatic’ presentations of distress (Kirmayer et al., 1993) and normalising attributions of depression have been associated with reduced recognition of depression by physicians (Kessler et al., 1999).

Nazroo (1997) argued that this ‘cultural distance’ from western psychiatric concepts explained the greater variance in depressive symptomatology accounted for by age on migration than English fluency alone, reduced symptomatology observed in those migrating later in life. However, it should be recognised that these findings might also reflect the adverse social circumstances greeting migrant populations.

The editors of DSM-IV have attempted to improve its cultural validity across ethnic groups through the inclusion of culture bound syndromes (common patterns of distress within certain cultures). Whilst this is a useful step forward, such actions serve to perpetuate the notion that the experiences of other ethnic groups deviate from the western ‘norm’ and are either viewed as ‘inexplicable’ or as simply ‘masking’ the underlying ‘universal’ disorder of depression (Klienman, 1987). This subsequently encourages the application of western treatment approaches to depression, which may not be consistent with the cultural representations of depression and self-construals held by ethnic minority populations.

Treatment issues
Where clinicians engage in ‘western’ cognitive therapy for depression without considering cultural variations underlying the experience of depression, treatment is unlikely to be successful. For example, culturally insensitive attempts to challenge critical thoughts/encourage self-enhancing patterns of thinking are likely to be met with resistance by the client holding interdependent values. Similarly, attempts to increase self-efficacy through...
undertaking activities associated with the achievement of personal, as opposed to group goals, are likely to be resisted where such activities serve no purpose for the ‘interdependent’ self.

Consistent with this Kasraz (2004) noted that treatment aimed at the individual, be it medical or psychotherapeutic conflicts with the ‘situational’ conceptualisations of depression by South Asian women. These women preferred to adopt more concrete help-seeking efforts, focussed on either solving the problem through seeking advice from other family members, or avoiding thinking about the problem altogether. Interestingly, these natural coping strategies were found to protect self-esteem from the negative impacts of discrimination in a sample of Korean immigrants in the United States (US) (Noh & Kaspar, 2003). Alternative strategies documented within religious individuals include the use of prayer (Lowenthal & Cinnirella, 1999) and spiritual healing among Asian populations in the UK (Bhui et al, 2004).

If help is sought, failure to acknowledge/incorporate existing coping strategies, perhaps by neglecting to include the family or minimising the importance of religious beliefs, will reduce the client’s willingness to collaborate in therapy. For example, it is argued that local spiritual and religious healing practices survive in many parts of the world because local healing succeeds where biomedicine fails, as it recognises the links between disease and social, moral and religious beliefs (Dein & Sembhi, 2001).

Furthermore, failure to consider cultural values and associated practices can lead to assumptions about the ‘appropriateness’ of certain culturally defined ways of behaving. For example, passivity expressed by women of interdependent cultures may reflect traditional gender roles rather than a lack of assertiveness. Failure to explore cultural values underlying such behaviours may result in treatment for depression being inappropriately targeted toward increasing the client’s assertiveness, which conflicts with the client’s culturally defined ways of behaving and expressing needs.

Upon reflection, Samira’s GP initially attributed her symptoms to an underlying physiological cause. Several months later, when no organic cause was found, she was referred to the mental health team. Despite recognising the emotional distress underlying her symptoms, the cultural significance of Samira’s presentation and subsequent implications for her treatment were not fully considered by the team. It is possible that our ‘western’ understanding of depression may have conflicted with the beliefs of Samira and her family, reducing their motivation to engage in therapy.
Shifting Cultural Orientations

Although the distinction between interdependent and independent cultures is important, increasing migration and globalisation patterns have shifted the understanding of cultural values associated with ethnicity from a closed, self-contained, system towards an ever-changing construct emerging from interactions between individuals and communities (Fernando, 1990). Subsequently, cultural values are no longer rigidly associated with eastern or western societies.

Consistent with this, studies have reported the co-existence of interdependent and independent cultural values in multi-cultural societies (Harrington & Lui, 2002) and acculturative or bicultural orientations (where the self is categorised in terms of minority and majority values) have been observed across all ethnic minority groups in the UK (Modood et al, 1997).

Diagnostic and treatment issues

Failure to acknowledge integrated sets of independent/interdependent values can confuse the diagnosis of depression. For example, if self-critical thinking patterns are automatically attributed to interdependent cultural values, distress may be underestimated in individuals holding values that are more integrated (where self-criticism is not associated with traditional ‘interdependent’ concepts of well being).

Increased involvement with the majority culture, through its impact on reducing feelings of anger and disillusionment, has been associated with reduced depressive symptomatology in immigrant populations (Cortes et al, 2003). It is, however, important to consider that, where the cultural values of some members of the family are changing faster than others (through increased exposure to the values of the host culture) conflicts are likely to occur as the individual struggles to reconcile their new ‘independent’ values with the traditional ‘interdependent’ values held by their family.

Research highlighting the importance of the family in non-western understandings of depression and subsequent help-seeking attempts can lead to assumptions that the family is a protective source of support for members of ethnic minority populations. Failure to explore potential conflicts within the family, encountered as cultural values change, could lead to the neglect of factors maintaining the client’s depression that may also be associated with an increased risk of self-harm or suicide. Consistent with this, the presence of liberal views within a more traditional family setting has been associated with suicide attempts in Asian women (Bhugra et al, 1999, cited in Bhugra & Desai, 2002).

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Furthermore, targeting interventions solely around interdependent values e.g. involving the family, adopting social, as opposed to medical conceptualisations of depression, may be inappropriate for individuals from more acculturated families, sharing western conceptualisations of depression. These issues can be explored further by thinking about Samira and her family.

In writing this essay, I became aware that Samira's cultural orientation was shifting at a faster rate than her parents, probably due to her increased exposure to western culture through the media and peers at school and this was leading to conflict at home, increasing Samira's distress. Inadvertently, the culturally insensitive attempts of the team to encourage Samira to meet her own independent values only served to create further conflict, through increasing the distance between the beliefs of Samira and her family.

DIFFERENCES WITHIN THE THERAPEUTIC RELATIONSHIP

The diagnosis and treatment of depression is further influenced by the therapeutic relationship between clinicians and clients of different ethnic backgrounds, as cultural stereotypes and beliefs held by both, are evoked through transference processes (Thomas, 1992).

Transference is a psychodynamic concept where fears, problems and emotions encountered within past situations are ‘transferred’ and relived within the consulting room (Thomas, 1992). This process is shaped by the social and historical contexts of client and clinician, influencing therapeutic interactions, regardless of theoretical orientation. For example, historic oppression, discrimination and systematic denial experienced by ethnic minority groups in the western world may produce feelings of fear, anger and suspicion toward members of the majority population. For the ethnic minority client these feelings may be ‘transferred’ when faced with a clinician representing the majority culture, jeopardising the openness of the therapeutic relationship (Jones & Seagull, 1997), essential for an accurate assessment of depressive symptoms. Consistent with this, cultural mistrust has been associated with reduced disclosure of intimate issues by African-Caribbean women toward white counsellors (Thompson et al, 1994).

For the white client faced with a clinician from the minority population, conscious/unconscious prejudiced beliefs, questioning their clinician's 'expertise', may become active which, if suppressed, could produce feelings of anxiety and anger toward the
clinician, hindering the development of a therapeutic relationship necessary for the accurate diagnosis of depressive symptomatology (Thomas, 1992).

Furthermore, the clinician’s failure to acknowledge transference underlying aggressive and suspicious behaviours, could produce inaccurate assumptions that the client is ‘paranoid’ (Fernando, 1990), clouding the detection of underlying depressive symptomatology.

However, the clinician is not immune from transference as unconscious beliefs surrounding their own ‘superiority’ over other ethnic groups are evoked within therapeutic encounters leading the client to feel ‘inferior’. This increases the power differential between client and clinician ultimately perpetuating the client’s feelings of inadequacy and worthlessness, maintaining their depression (Thomas, 1992).

There is danger that where clinicians become aware of their own transference they may react by adopting a level of ‘colour-blindness’, endeavouring to treat clients from different ethnic populations in the same way, regardless of cultural differences. Adopting such ‘politically correct’ approaches is counter-productive in gaining an accurate assessment, as colour-blind attitudes are associated with reduced empathy toward the client (Burkard & Knox, 2004) and increased clinician cultural awareness is associated with increased disclosure of ‘intimate’ issues by African-Caribbean women (Thompson et al, 1994).

A naïve view that matching the ethnicity of the client and clinician may serve to eradicate such difficulties can be countered, as this does not always remove the intrusion of social class differences and stereotypes held by both parties. Furthermore, resentment felt by the client toward the ‘success’ of their clinician, where hidden by the client and not discussed within therapy, will again exacerbate feelings of inadequacy and worthlessness, maintaining the client’s depression (Thomas, 1992).

This research has increased my awareness of issues relevant to Samira’s treatment. The team, through a desire to be politically correct, may have adopted a ‘colour-blind attitude’ failing to discuss race and culture-related issues through fear of causing offence. This may have hindered attempts to be empathetic and engage with Samira and her mother, ultimately reducing their disclosure of issues pertinent in formulating an effective intervention.
CONCLUSIONS

Throughout this essay, I have raised numerous issues surrounding the treatment and diagnosis of depression within ethnic minority populations, demonstrating my awareness of how the ethnocentric tendencies of the team influenced Samira’s treatment. It seems apt to conclude by summarising pertinent diagnosis and treatment issues raised within a set of recommendations for effective clinical practice.

Although language barriers will influence clients’ abilities to communicate their difficulties, clinicians should remain mindful that, even when obtained through the process of translation, expressions of distress might vary from western conceptualisations of depression. Subsequently, culturally sensitive approaches should be employed to avoid underestimating the client’s depressive symptomatology and subsequent risks to themselves and others. Primarily, such approaches should look beyond symptoms, illness category and presentation, (Fernando, 1990) considering patterns of distress among certain populations through exploring the individual’s wider socio-cultural context (e.g. language, cultural idioms of distress, and cultural concepts of health) within assessment in order to inform subsequent treatment options. Furthermore, attention to socio-economic difficulties, in the context of a somatic presentation, may highlight factors maintaining depression through their negative impact on self-esteem.

Consideration should also be given to whether the stigmatising effects of diagnosing ‘depression’ will be useful for the client, or whether it may be more effective to consider some euphemism that is more culturally acceptable and less stigmatising (Klienman, 1987).

Whilst arguments exist for the adoption of culture-specific ‘indigenous therapies’ when working with members of ethnic minority populations, I would agree with Owusu-Bempah (2002) who argued that in an era of increasing globalisation and migration it is not practical for any clinician to become ‘expert’ on beliefs and practices relating to mental health in all ethnic groups. Such approaches continue to view other cultures as ‘different’ or ‘abnormal’. Furthermore, I believe assumed familiarity with different cultural values could lead to inaccurate assumptions and generalisations based on previous experience with individuals of the same ethnicity. I would subsequently advise the clinician to adopt a ‘curious’, rather, than expert approach to the exploration of cultural values pertinent to the client’s presentation. In encouraging the client to be their own cultural ‘expert’, the power differential between
client and clinician is subsequently reduced and a more accurate understanding of pertinent cultural issues is gained.

Where racially related transference from the client is identified, it will need to be addressed openly if therapy is to succeed. The clinician will also need to become familiar with their own beliefs in order to ensure that they do not influence the therapeutic relationship, possibly through personal therapy.

Whilst therapy does not need to be a specifically designed treatment package targeting individuals of ethnic minority groups in certain ways, it should consider the relevant socio-cultural context of these various groups.

Subsequently, consideration should be given to more flexible treatment approaches integrating family and systems-level interventions, shifting the focus from western cognitive understandings of depression, toward the relationship between the individual, their cultural values and those of their family.

Cognitive approaches to depression should not, however, automatically be discarded. Where individuals hold integrated cultural values not conflicting with those of their family, individual psychotherapy may be appropriate. Furthermore, consideration should be given to the impact of traditional ‘interdependent’ values on the therapeutic process, employing flexible approaches in attempts to challenge patterns of self-critical thinking, assertiveness training and exercises aimed engaging the client in activities geared toward the achievement of personal goals.

If clinicians are to work effectively within ethnic minority populations there must be flexible approaches to diagnosis and treatment, looking beyond western conceptualisations of depression. Crucially, clinicians must recognise that ‘culturally sensitive’ attempts to target therapy toward stereotypical understandings of ‘interdependent’ cultures may be inappropriate. In an era of increasing globalisation, cultural orientations no longer fall into distinct interdependent/ independent categories. Subsequently attempts to acknowledge cultural differences, without thorough exploration, are as dangerous and inappropriate as ethnocentric ‘colour-blind’ approaches, disregarding the client’s ethnicity/culture. Therefore, client centred explorations are necessary if diagnosis and treatment for depression is to be undertaken successfully within ethnic minority populations.

To What Extent is Membership of an Ethnic Minority Group (in the UK) Influential in the Diagnosis and Treatment of Depression
REFERENCES


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To What Extent is Membership of an Ethnic Minority Group (in the UK) Influential in the Diagnosis and Treatment of Depression
"Under the proposed reforms to the Mental Health Act Clinical Psychologists will be able to assume greater involvement in the processes of 'sectioning' and supervising the treatment of people who are subject to compulsion. What are the advantages and disadvantages of our profession getting involved with these processes? What issues and dilemmas might need to be considered by Clinical Psychologists as they make a decision about whether or not to accept these responsibilities? How would you decide?"
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Issues to be Considered by Clinical Psychologists Assuming Formal Powers Under the Mental Health Act
In July 1998, the Government launched the first root and branch review of British mental health law since the 1950s, subsequently subjecting several draft bills to intense pre-legislative scrutiny (Department of Health [DoH], 1999, 2000a, 2000b 2002). The most recent Draft Mental Health Bill (DMHB, DoH, 2004) hails a controversial shift to the roles of Clinical Psychologists employed within the National Health Service (NHS), granting them formal powers within the processes of ‘sectioning’ and supervising Compulsory Community Treatment Orders (CCTO’s).

This essay raises ethical and professional issues pertinent to Clinical Psychologists assuming formal powers under the Mental Health Act (MHA). Being a trainee Clinical Psychologist, researching these issues has proved influential in shaping my own thoughts about the proposed changes. In order to reflect upon these changes within this essay, I begin by presenting an overview of my previous experiences working with people treated under the MHA and my stance on the issue of assuming formal powers prior to beginning this essay.

I shall then summarise the social/political factors shaping the MHA’s development, before outlining the principles of the DMHB. I will subsequently present an overview of the ethical and professional issues proving most influential in shaping my stance on assuming formal powers. These discussions will include an exploration of pertinent issues to be considered by Clinical Psychologists regarding: the necessity/discriminatory capacity of CCTO’s; whether Clinical Psychologists will operate more humanely; and the impact of these changes on our therapeutic relationships with clients. I will conclude by summarising the issues raised and their impact on my opinion with regard to assuming formal powers.

My Experiences of Working with People Treated under the MHA
In beginning this essay I reflected upon my experiences of working with individuals in crisis, subsequently summarising them below.

During my Adult Mental Health placement I had been unable to undertake any therapeutic work with individuals in crisis; I therefore chose to ‘shadow’ staff and ‘patients’ at a local ‘Psychiatric Inpatient Unit’. This was my first encounter with ‘secure’ settings and it elicited strong feelings within me. I was shocked by the physical conditions within the ward: the

As a Clinical Psychologist in training I will undoubtedly be affected by the proposed reforms to the MHA. As such, due to the reflective nature of this essay I shall where appropriate use the terms ‘our’ and ‘we’ to reflect issues to be considered by the profession of Clinical Psychology as a whole.

Issues to be Considered by Clinical Psychologists Assuming Formal Powers Under the Mental Health Act
locked doors and CCTV cameras; envelopes containing personal possessions locked securely out of reach and the sterile smell/furnishings. More upsetting was seeing Sally, a woman diagnosed with ‘Schizophrenia’, telling staff that she believed her family were being physically attacked in the next room. Sally’s distress escalated as she was first talked over and subsequently ushered out of the room to enable discussions about her medication to continue. After Sally desperately tried to force her way back in, begging staff to help save her family, she was physically barricaded out of the room to prevent further ‘disruption’ to the ward round.

I left this experience questioning whether such an environment could be considered ‘therapeutic’ and hoped that by assuming formal powers Clinical Psychologists\(^4\) could prevent similar losses in dignity in the future. These experiences proved important in shaping my own beliefs and are likely to have influenced my approach to this essay. In order to remain mindful of this fact, I will, where appropriate, reflect upon these experiences throughout this account.

**HISTORY AND CONTEXT INFORMING THE MENTAL HEALTH ACT**

Before 1900, it was commonplace to detain individuals suffering from ‘mental illnesses’\(^5\) to ensure their segregation from the public. Willingness to ‘integrate’ these individuals within society did not emerge until the 20\(^{th}\) century, following the growth of the psychiatric specialism and subsequent developments in psychotropic medication. These changes initiated the development of the 1959 MHA which guided the *treatment* (as opposed to detention alone) of individuals with ‘mental illness’. This legislation saw terms such as ‘detention’ replaced by ‘compulsory admission’ or ‘sectioning’ and led to a shift in the locus of treatment away from the hospital, towards community settings (House of Lords, House of Commons [HLHC], 2005)

The 1959 MHA prevailed until social understandings of mental illness grew during the 1960s/70s, after which, the ‘paternalistic’ guidelines of the Act became regarded as an abuse of professional power. As such, the Act was reformed in 1983 and although ‘care in the community’ continued, new safeguards were introduced to protect the rights of those treated under the Act (HLHC, 2005).

\(^4\) It is beyond the scope of the essay to provide a detailed account of all the ethical issues to be considered by Clinical Psychologists assuming formal powers under the MHA.

\(^5\) I dislike the terms ‘mental illness’ and ‘mental disorder’ there will, however, be occasions when the use of such terms is necessary to reflect the research of other authors/societal attitudes relevant to the topics under discussion.

Issues to be Considered by Clinical Psychologists Assuming Formal Powers Under the Mental Health Act
Context of the Proposed Reforms
The proposed reforms occur against a backdrop of increased public scepticism with regard to the efficacy of community care. These attitudes have been fuelled by news coverage of selected incidents where individuals receiving ‘community care’ attacked members of the public and terms such as ‘Dangerous and Severe Personality Disorder’, leading to confusion about the ‘dangerousness’ of people with mental health difficulties (HLHC, 2005). Whilst these attitudes have driven governmental plans to reform the MHA toward emphasising ‘public protection’, the publication of the Human Rights Act (1998) created a need to balance reforms toward protecting the rights of the individual.

Principles of the New Act
The DMHB (DoH, 2004) proposes several changes to the MHA. Primarily, it replaces previous definitions of ‘mental illness’ with the term ‘mental disorder’ (referring to ‘any impairment/disturbance of the mind/brain resulting from a disorder/disability of the mind/brain’). This broader definition aims to make treatment under the MHA more accessible to individuals who would have been denied treatment without a specific diagnosis, under the categorical confines of the 1983 MHA (DoH). The DMHB aims to ensure that mental health care is accessible to all irrespective of co-morbid diagnosis or capacity (Taylor et al, 2003) by removing all exclusions to this definition (e.g. substance misuse, learning disabilities, sexual deviancy) and making ‘sectioning’ and compulsion non-dependent upon an individual’s capacity to refuse/accept treatment.

The interests of the person will also be protected by permitting individuals to appoint an independent advocate to help them access information about their rights throughout treatment and the introduction of safeguarding provisions requiring mental health professionals to seek independent authorisation from a ‘tribunal’ if detaining a person beyond 28 days (Grounds, 2001). ‘Patient’ care will also be ‘enriched’ by reducing the risk of social exclusion stemming from hospitalised detention/treatment through extending compulsory treatment orders to community-based settings.

Finally, the DMHB will extend the lead responsibility in both ensuring compliance with CCTO’s and assessing whether individuals continue to meet the criteria for compulsion from Psychiatrists alone to Consultant Clinical Psychologists under the role of ‘Clinical Supervisor’.

Issues to be Considered by Clinical Psychologists Assuming Formal Powers Under the Mental Health Act
ETHICAL DILEMMAS TO BE CONSIDERED BY CLINICAL PSYCHOLOGISTS ASSUMING FORMAL POWERS

Is Compulsion Necessary?
In considering the proposed changes to our professional role, it is important to question the rationale underlying CCTO’s. The DMHB (2004) proposes that through extending compulsory treatment orders into the community, patient care will be enriched by preventing, through early intervention, social exclusion associated with hospitalisation and incidences of relapse in the community. Under current legislation a patient discharged from hospital but choosing not to take their medication or attend therapy sessions, cannot receive further treatment until their distress has reached a level deemed to warrant further in-patient care. This ‘revolving door’ system is a documented source of anxiety/frustration for many mental health professionals and is frequently linked to episodes of ‘patient’ self-harm/violence in the community (Laurance, 2003).

Whilst it is important to recognise that some individuals previously detained under the MHA now believe that detention/compulsion was a necessary part of their treatment (Bradford et al, 1986 cited in Ross, 2003), it is possible that these beliefs may have been shaped by wider societal assumptions about dangerousness and the need for social control (Ross, 2003). Consequently, in considering whether I would want to assume formal powers, I chose to explore the validity of societal fears underlying the proposed reforms: namely, that individuals suffering from ‘mental illnesses’ are ‘dangerous’ to themselves and others and that medication/forced treatment will reduce this risk.

Contrary to media ‘hype’, research indicates that there has been no increase in murders committed by people diagnosed with a “mental illness” since the introduction of community care in the 1950’s (Taylor & Gunn, 1999). Although self-harm may occur more readily among individuals in crisis, there is evidence to suggest that overall rates of suicide/violence may relate to factors other than medication usage/treatment (Holmes, 2002). Specifically ‘mental illness’ is observed to be a relatively weak predictor of violence (Rogers & Pilgrim, 2003) and suicide (Shahtahmasebi, 2003) when compared to drug/alcohol use, socio-economic status, gender and history of violence.

When looking to countries such as the United States (US), where community treatment orders are already in place, the New York study (Steadman et al, 1998), failed to observe significant reductions in re-hospitalisation/arrest rates, psychiatric symptoms or improvements in quality

Issues to be Considered by Clinical Psychologists Assuming Formal Powers Under the Mental Health Act
of life among those treated under CCTO’s. A second US study (Ridgley et al, 2001), although observing some reduction in arrests and re-hospitalisation rates, also failed (due to methodological constraints) to observe superior gains over those obtained through non-compulsory treatment and assertive outreach programmes. Separate American findings also observed that 47% of individuals previously detained, described feeling frightened of re-accessing mental health services, for fear of being placed under a CCTO (Campbell & Schraiber 1989, as cited in Rolfe, 2001). Similar findings have been observed in Australia (Power, 1999, as cited in Rolfe, 2001).

Of course it is important to consider that cultural variations in American attitudes toward ‘mental illness’ may have influenced these findings. Specifically, the absence of an NHS and disparities between insurance cover for mental and physical health treatment (Mark et al, 2003) may have exacerbated US findings. Yet despite these differences, it is important to consider the potential implications of these findings. Primarily, there is evidence to suggest that the risk posed by individuals in crisis is both inflated and underlied by factors other than medication/treatment. Consistent with this, there is evidence that compulsory treatment in the community may be no more effective in improving quality of care and reducing relapse rates than voluntary treatment procedures, questioning the need for CCTO’s. Consequently, Clinical Psychologists must question whether the only ‘benefit’ of CCTO’s is their potential to reduce inpatient care costs. Consequently, are we in danger of becoming involved within a process that discriminates against individuals with ‘mental health problems’?

Will We Become Party to a Discriminatory Process?
We already know that for a host of interrelated and complex reasons individuals from black and ethnic minority populations are more often: diagnosed as ‘schizophrenic’; detained and subjected to compulsory treatment; and receive higher doses of medication than other service users (Fernando, 1995). Subsequently, in addition to questioning the efficacy/necessity of CCTO’s, Clinical Psychologists must consider whether changes to the Act’s terminology and increased emphasis on risk assessment, will increase the risk of extending these discriminatory practices toward wider sections of society.

Changes to the act’s terminology
The DMHB’s revised definition of ‘mental disorder’ is now non-dependent on diagnosis. As such, without any objective criteria to guide assessment, there is a danger that people may be categorised as ‘mentally disordered’ on the sole basis that their behaviour is regarded as somehow unusual, offensive or different from our own. When we combine this risk with the
DMHB’s failure to exclude groups of individuals whose behaviour may be exacerbated by factors other than ‘mental disorder’, the following groups may be especially vulnerable to discrimination: those with learning disabilities/communication disorders who may be less able to express their feelings in socially appropriate ways (Holmes, 2002); those whose cultural expressions and representations of distress differ from our own or exacerbated by longstanding social inequalities associated with their race/social standing; those whose behaviours are exacerbated by drug/alcohol intoxication. In addition, individuals with ‘Personality Disorders’ (PD) who are already subject to moral judgements about their failure to achieve ‘mature autonomous adult functioning’, (due to PD’s contested diagnostic status, Pilgrim & Hewitt, 2001) may be especially vulnerable to this kind of subjective or moral discrimination.

Furthermore, the failure to include an assessment of capacity within the criteria for compulsion/detention renders individuals with learning disabilities, communication disorders and those with non-violent personality disorders (all of whom may present with unusual behaviours in an absence of any pathognomic markers of specific ‘mental illnesses’), particularly vulnerable to additional discrimination. This risk is exacerbated by the DMHB’s emphasis on the existence of ‘appropriate treatment’ within the criteria for compulsion. Consequently, people may be detained for treatment of their presenting problem (e.g. anxiety/depression), despite there being no proven effective ‘treatment’ for the learning disability/‘personality disorder’ underlying their difficulties.

Before considering whether we wish to become party to such a process, Clinical Psychologists must acknowledge that the potential risk of discrimination is further compounded when changes to the Act’s terminology are considered alongside the DMHB’s increased emphasis on risk assessment.

Risk assessment
The current DMHB allows compulsory powers to be applied when an individual’s behaviour, by product of their ‘mental disorder’, places them at risk of self-harm, neglect of personal health/safety, or necessitates the protection of others.

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6 Although ‘mental health problems’ do occur among individuals with learning disabilities (Moss, 2000) and alcohol/substance dependency (Jenkins, 1997) many individuals from these populations do not experience such difficulties.

7 Please refer to Pilgram & Hewitt (2001) for a more detailed account of issues raised by the MHA for individuals with ‘Personality Disorders.

Issues to be Considered by Clinical Psychologists Assuming Formal Powers Under the Mental Health Act
As Clinical Supervisors will play an important role in reviewing whether individuals continue to meet these criteria (HLHC, 2005) it is important to consider ethical and professional dilemmas attached to the prediction of risk. We know that the process of risk assessment and prediction is highly complex and often fraught with difficulties (Crawford, 2000). We also know that many studies supporting the accuracy of clinical and actuarial risk assessment measures (Dolan & Doyle, 2002) fail to take into account a natural base-rate at which violence/self-harm occurs within the population. This base-rate, when accounted for, can render the prediction of risk inaccurate as many as 9 times out of 10 (Szmukler, 2001).

Clinical Psychologists are subsequently faced with the possibility of assuming active roles within a process where the accurate assessment of risk has important consequences for people’s personal liberty, but where the validity of existing risk assessment tools remains questionable. This, in itself represents a further form of discrimination, as only those individuals whose behaviour is in someway different/unusual (irrespective of whether these behaviours are exacerbated by learning disabilities, socio-cultural differences or intoxication) will be subjected to assessment using these tools. Furthermore, when considering these inaccuracies alongside the DMHB’s emphasis on ‘public protection’, we must question whether pre-existing risk assessment measures can be effective in ascertaining whether ‘public protection’ is warranted; clearly a more arbitrary and less quantifiable requirement than establishing if someone is at risk of undertaking specific forms of violence/self-harm.

Similarly, given the absence of exclusion criteria under the DHMB Clinical Psychologists must consider the validity of their pre-existing risk assessment tools in predicting behaviour among populations where expressions of distress may vary from those on which the measures were piloted (e.g. ethnic minority and learning disabled populations). In exploring these issues, the extent to which our assessment methods are valid in assessing individuals intoxicated with drugs/alcohol must be investigated. Although inexperienced in this domain, I would imagine that intoxication may complicate attempts to separate those aspects of a person’s ‘unusual’ behaviour stemming from ‘disorder of the mind/brain’ from those caused by drugs/alcohol. The presence of intoxication could thus further inflate the possibility that individuals may be detained purely because of their unusual behaviour.

Ethically, Clinical Psychologists must also consider what exactly they will become party to ‘protecting people’ from, given that the purported risk posed by individuals with mental health problems is questionable. This raises the possibility that assuming formal powers will transform us into agents of ‘social control’, detaining individuals under the guise of
‘protecting others’ when all we are protecting people from is the anxiety/unease associated with living in close proximity to those whose behaviour differs from that defined as socially appropriate (HLHC, 2005).

**Will we be Better at Making Decisions?**

Of course those in favour of Clinical Psychologists assuming formal powers propose that, by virtue of our training, we will be better placed to reduce the risks of discrimination under the MHA. In contemplating this question it is necessary to consider the skills Clinical Psychologists may bring to their proposed roles under the MHA. A central element within clinical training is the development of ‘formulation skills’ whereby assessment information is integrated within a comprehensive understanding of the aetiology and maintenance of an individual’s difficulties (Bruch, 1998). Consequently, through making psychological formulation central to care planning processes and developing clinically appropriate and less ‘medicalised’ care plans, it is hoped that Clinical Psychologists will be better placed to ensure the delivery of ‘best care’ to meet their clients’ needs (Taylor *et al*, 2003).

Whilst the potential to implement more creative care-plans is a possible benefit of assuming formal powers, Clinical Psychologists must consider whether the perceived professional differences between ourselves and our ‘medical’ colleagues will, in practice, be realised. Menzies (1959) proposed that many institutionalised hospital practices evolved in order to strengthen staff defences against the exceptionally anxiety-inducing nature of their work. Although Menzies was not explicitly referring to mental health treatment, it is possible that the systems of the MHA could represent similar unconscious attempts to distance ‘staff’ from their ‘work’. Under the proposed DMHB Clinical Psychologists will not only play a role in supervising CCTO’s and reviewing whether individuals continue to meet criteria for compulsion, they may also be able to prescribe treatments such as Electro-convulsive therapy. Aside from the ethical dilemmas elicited by recommending treatments without having been formally trained in their bio-chemical methods of action/side-effects, Clinical Psychologists must consider whether the potential consequences of such decisions (detaining individuals/subjecting them to ECT) will lead us to distance ourselves from our clients in an effort to reduce anxiety elicited by ‘identifying’ with them and the results of our professional choices (Newnes, 2003). It has already been suggested that Clinical Psychology, as a profession, colludes with ‘medical’ approaches to mental health by adopting medical terminology and diagnoses as methods of re-conceptualising human distress (Newnes, 2003) e.g ‘Cognitive Therapy for ‘Depression’, Beck, Rush, Shaw & Emery, 1979). Consequently,

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8 Providing the client and Mental Health Tribunal agree.

**Issues to be Considered by Clinical Psychologists Assuming Formal Powers Under the Mental Health Act**
we must consider whether assuming formal powers will lead to an extension of these tendencies by adopting discriminatory/defensive practices.

Will clinical psychologists operate more humanely than other professions?
In addressing this question it is necessary to reflect upon other skills possessed by Clinical Psychologists, a task aided by my own ongoing progression through the Clinical Psychology training program within which the ability to acknowledge and reflect upon emotional reactions elicited within work is continually emphasised. As trainees we are taught to embrace and reflect upon these reactions and, where appropriate, use them to inform our formulations and practice. This often involves questioning whether anxious feelings represent valid concerns for our clients, or pressures from the wider system within which we operate. When recalling my own experiences observing on the wards, I considered how my supervisor had helped me to reflect in this way.

During one of my visits, I observed a Psychiatrist assessing whether a young white male (Paul), who had been diagnosed with ‘Schizophrenia’, could return home to see his girlfriend for the weekend. I was struck by how desperate Paul was to return to some ‘normality’ by escaping the ‘confines’ of the ward and I was aware that if I were in his position, I would undoubtedly feel the same. However, when considering the responsibilities of the Psychiatrist I became aware of my own growing anxiety, the potential negative consequences of being held accountable for allowing Paul home should anything ‘go wrong’, at the forefront of my mind. Through supervision, I was able to consider whether this anxiety stemmed from my own early stage in training and wider societal attitudes towards people with ‘mental illness’, as opposed to a genuine concern for Paul’s welfare.

Although Holmes (2002) argues that it is arrogance to assume that Clinical Psychologists will be better placed to resist these pressures than any other group of mental health professionals, my experiences led me to consider whether Clinical Psychologists, through utilising reflections elicited within regular supervision, may be able to facilitate the reflective capacities of their colleagues, thus reducing defensive/discriminatory practices. In considering this, we must acknowledge that the extent to which discriminatory practices can be reduced is likely to be restricted by the ‘protective’ legislation of the DMHB. Consequently, given that our ability to exert change within the system may be limited, we must remain aware of how being associated with ‘sectioning’/compulsion may influence our capacity to develop therapeutic relationships with our clients.
Will Assuming Formal Powers Alter Relationships with our Clients?

In contemplating whether our therapeutic relationships would be changed by assuming formal powers, I found it helpful to consider how individuals ‘treated’ under the MHA experience the processes of ‘sectioning’ and ‘compulsion’. As such, I have chosen to present, a brief overview of the literature in this area, before moving onto explore how the experience of being ‘sectioned’ influences attitudes towards mental health professionals and the subsequent ethical dilemmas raised for Clinical Psychologists assuming formal powers.

The experience of ‘sectioning’

In attempting to consider the experience of being ‘sectioned’ I reflected further upon emotional reactions elicited within me during my time observing on the wards. Specifically, I recalled how anxious, confused and, to some extent, powerless I had felt about whether to question the staff’s actions after witnessing Sally’s premature removal from the ward-round. At the time, I reflected within supervision upon whether “patients” would experience similar emotions when being “treated” on the ward and if so, the likelihood that these emotions would be intensified by the potential consequences of challenging staff - in terms of further restrictions to their personal liberty - if these challenges are regarded as further evidence of ‘mental disorder’.

Consistent with this, feelings of unworthiness, vulnerability, fear and lack of control have been reported by individuals treated under the MHA (Hesford, 1992 as cited in Ross, 2003), the experience of being forcibly medicated being described as especially de-humanising and degrading (Holmes, 2002). In addition, psychiatric admissions have been observed to be accompanied by significant amounts of distress, with some individuals subsequently developing symptoms of post-traumatic stress associated with the admission (Morrison et al, 1999).

How does treatment under the MHA affect attitudes towards professionals?

Research based on Rotter’s Locus of Control Theory (1966) has observed that individuals suffering from ‘psychosis’ are more likely to attribute negative experiences associated with being sectioned to external sources e.g. professionals/family, whilst those suffering from ‘depression’ will attribute such experiences to internal causes e.g. some aspect of their own personality/behaviour (Kinderman & Bentall, 1996). Consistent with this, many individuals treated under the MHA described becoming blaming and mistrustful of health professionals and services (Holmes, 2002).
Similarly, if we consider cognitive theories of 'psychosis' (Freeman et al, 2001) persecutory thinking is argued to be accompanied by underlying schemas which regard: the self as vulnerable/unsafe; others as mistrustful/devious and the world as unjust/unfair. Consequently, where a person's life-experiences have been characterised by lack of control/injustice – regardless of their presenting difficulty (individuals with learning disabilities/from ethnic minority groups) - the very process of being detained/forcibly medicated could reinforce beliefs about the self/others, perpetuating distress and irrevocably damaging their capacity to trust mental health professionals associated with such processes.

**Dilemmas for Clinical Psychologists**

Until now, Clinical Psychologists have been regarded as largely separate from 'compulsion' and 'sectioning' and as such have been somewhat protected from the blaming and mistrustful attitudes of 'patients' towards those professionals assuming more active roles within these processes. Consequently, in deciding whether to assume formal powers, Clinical Psychologists are faced with a number of ethical dilemmas.

Primarily, we must consider whether involvement within these processes will cause our clients to feel blaming and mistrustful towards us, compromising the collaborative nature of psychological therapy and damaging our capacity to develop therapeutic relationships with them. This capacity may be further compromised if we begin to distance ourselves from our clients' (as a defence mechanism), reducing our ability empathise with them.

However, I would argue it is naïve to assume that Clinical Psychologists are immune to the coercive powers of the MHA within their current roles. For example, consider the use of terms such as 'duty of care' and 'boundaries of confidentiality' within the process of gaining informed consent. These terms already convey an important yet subtle message to our clients; namely that should their behaviour become too worrying for us, 'confidentiality' will be disregarded and if deemed appropriate, they too may find themselves 'assessed' under the MHA. As such, if these influences are already active within our work, are we discounting the possible benefits of our involvement in the MHA (e.g. informing care plans etc) prematurely?

Of course the crucial distinction between these pre-existing power imbalances and those hailed by the DMHB is that at present, the client retains the right to choose whether they will attend sessions and the nature of the information disclosed within those sessions. For those

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9 The therapeutic relationship is commonly regarded as the most important mechanism of change within all psychological approaches and is dependent upon the therapist's ability to engage the client within an open and trusting, equal relationship.
clients subject to compulsion under the MHA this choice and thus the sense of autonomy for ones self and future are removed. Whilst it may be hypothetically possible, ethical issues aside, to ‘force’ individuals to comply with medication programmes in the community, it remains to be seen whether anyone can be ‘forced’ to benefit from and engage within cognitive, behavioural or psychodynamic therapy sessions. We know that engendering a sense of self-efficacy and empowering our clients is important within of this process and that this occurs more easily within equal and collaborative therapeutic relationships. Consequently, the possibility of facilitating such changes when individuals are attending sessions under the threat of re-hospitalisation is questionable.

Whilst it is important to remember that those assuming formal powers will not be forced to accept the role of a Clinical Supervisor for clients with whom they are already working therapeutically/where their skills would be better employed within a therapeutic role (Taylor et al, 2003), we must acknowledge that once our role becomes associated with the possibility of compulsion, client beliefs that their consent and choices will be irrelevant may follow (Monahan et al, cited in Ross, 2003), limiting our capacity to foster therapeutic relationships with all our clients, not just those subject to compulsion.

**SUMMARY AND CONCLUSIONS**

Throughout this essay I have highlighted a number of issues to be considered by Clinical Psychologists assuming formal powers under the MHA.

Whilst the Government argues that detention/compulsion is necessary for the protection of both the individual and the wider public, I have argued for greater consideration of the societal context informing and surrounding these changes. I have drawn attention to the possibility that Clinical Psychologists could become party to a system where individuals are discriminated against, purely on the basis that their behaviour differs from our own; a risk increasing once the impact of changes to the Act’s terminology on the validity of our pre-established risk assessment measures is considered. I have also argued for a greater consideration of the possible impacts of becoming embroiled within a discriminatory process on our professional identity and subsequent capacity to develop therapeutic relationships with our clients, questioning whether it is ethically appropriate/possible to force individuals to engage with psychological treatment programmes.
Whilst I do not wish to ‘sit on the fence’, or become a passive bystander observing such changes, I now regard my initial hopes of crusading against the mental health system (through assuming formal powers), as somewhat naive. Instead, I believe that in considering the dilemmas attached to assuming formal powers, we must reflect upon the underlying ethos of our profession: namely that as Clinical Psychologists we pride ourselves on being both ‘reflective scientist-practitioners’ and on conducting ‘evidence-based practice’. Consequently, prior to immediately disregarding or assuming formal powers, I believe our efforts should be directed toward stimulating attempts to debate, research and cross-examine the issues I have raised at both intra and inter-disciplinary levels.

In view of the questionable efficacy of CCTO’s, we must consider alternative approaches for dealing with individuals in crisis, *prior* to assuming formal powers. For example, Rufus May (in May *et al*, 2003), a Clinical Psychologist previously treated under the MHA, proposes three important principles for intervening in crisis situations which potentially avoid the need for compulsory treatment orders: give the person clear information about how their behaviour is perceived; acknowledge and explore their concerns; provide clear choices about how they can manage their mood/behaviour. With regards to therapeutic work, Hagan and Smail (1997) suggest that Clinical Psychologists should facilitate a recognition that an individual’s distress may be caused by powers beyond their control, including those within the wider societal and political system. Whether this can be achieved once we too are regarded as part of the ‘system’, remains uncertain.

We must also guard against distancing ourselves from those with whom we work by adopting a “there but for the grace of God go I” position acknowledging similarities between ourselves and our ‘clients’, whilst accepting that we may become users of mental health services ourselves (Newnes, 2003). As such, we must consider what we would want from services and whether being detained against our will, forcibly medicated and subject to systems which force us to attend therapy sessions or else be re-hospitalised are high on our list of priorities.

Although assuming formal powers is one *potential* means of altering these practices (through raising our professional profile and remit), I am unsure whether this is the only, or indeed best, means of achieving such change. Whilst the nature of our supervisory relationships and reflective training may render Clinical Psychologists better placed to cope with the emotional impact of assuming formal powers, so long as wider societal attitudes and stigma toward individuals with mental health problems persist, legislatory pressures to adopt defensive/discriminatory practices, will remain. Furthermore, our capacity to facilitate change

Issues to be Considered by Clinical Psychologists Assuming Formal Powers Under the Mental Health Act
from the top down is likely to be presided over by a legally dominated, Mental Health Tribunal (DMHB, 2004). Consequently, I agree that it is arrogance to assume, without further debate, that Clinical Psychologists will be any better placed to resist these pressures than our medical colleagues (Holmes, 2002). Instead, I would welcome attempts to explore alternative mechanisms of facilitating change in wider societal attitudes driving the MHA from the bottom up, possibly through raising awareness and understanding of crisis among our colleagues and the wider community.

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Issues to be Considered by Clinical Psychologists Assuming Formal Powers Under the Mental Health Act


**Issues to be Considered by Clinical Psychologists Assuming Formal Powers Under the Mental Health Act**
PROBLEM BASED LEARNING ACCOUNT:

YEAR 1

Year 1: March 2005
PROBLEM BASED LEARNING - REFLECTIVE ACCOUNT

In September 2004, a group of Clinical Psychology trainees, in their first week of training, were assigned a new type of ‘Problem Based Learning’ (PBL) task, requiring them to tackle the problem ‘The Relationship to Change’ working within small groups. Over the course of six weeks, trainees were instructed to reflect upon their own personal experiences of change, applying these reflections to their future clinical practice.

This essay provides a reflective account of my experience of the PBL exercise and comprises a number of sections. Firstly, I shall briefly outline the approach adopted by my PBL group, before reflecting, with the benefit of hindsight, upon my own personal experience of the initial part of the PBL process, demonstrating links I have observed between this and clinical practice. Subsequently, I shall reflect upon the theoretical approach adopted by my group in the light of my clinical practice on placement. Throughout the essay I shall be writing in the first person to demonstrate my reflexivity.

Members of my PBL group explored their personal experiences of change in relation to the decision to apply for the Clinical Psychology training program, reflecting upon these experiences from both personal and theoretical perspectives by mapping our personal experiences of the chosen transition onto the Transtheoretical Model of Change (Prochaska & DiClemente, 1983).

This model is essentially an integrative model of intentional behaviour change, typically adopted by Health Psychologists working within the fields of addiction. The model focuses on individual decision-making processes involved in modifying problem health behaviours or acquiring new positive behaviours and centres around five stages of change. These range from pre-contemplation stages, where there is no awareness of change, through more active contemplation of changing, preparation for change, action toward achieving change and maintenance of changed behaviours. Various ‘processes of change’ occur independently throughout, including ‘decisional balance’ scales weighing the pros and cons of change behaviours.

The group’s final presentation comprised a role-play of our personal experiences of the defined transition, using the model as a backdrop and highlighting factors crucial in our

10 Throughout the essay the term ‘model’ refers to the Transtheoretical Model of Change (Prochaska & Diclemente, 1983)
progression through the five stages. Links were then made between personal experiences of change (in light of the model) and clinical practice.

Reflections on the Process of the PBL Exercise
Throughout the PBL exercise, I kept a reflective journal. When reading this, I observed that my initial experience of the exercise was dominated by feelings of confusion and anxiety surrounding my perception of the 'abstract' nature of the task.

Other members of the group reported finding the nature of the task similarly 'abstract' and with the final presentation looming, collective levels of anxiety rocketed! Initially, our response was to seek a structure to impose on the process and relieve our anxieties about 'getting it wrong'. Given the importance of 'evidence-based practice' within Clinical Psychology, the group felt that finding a theory 'explaining change' would achieve this. Subsequently, the Transtheoretical Model of Change (Prochaska & Diclemente, 1983) was adopted.

Since starting my placement, I have become aware of similar anxieties experienced by myself as a first-year trainee, whereby there is often a tendency to adopt more structured patterns of assessment questioning and seek theoretical approaches, often perceived as providing a more structured 'cook-book' guide to therapy. For example, Hawton et al (1989) and Padesky (1997) both provide structured approaches to cognitive-behavioural assessment and intervention.

Whilst such an approach undoubtedly serves a purpose in relieving natural anxieties about 'knowing the right questions to ask', ensuring that key areas of information are covered, there are risks attached to applying theoretical models on the basis of a desire for structure rooted in personal anxieties about being 'good enough'. For example, during the PBL exercise, I experienced difficulties mapping my own personal experience of change onto a model constructed for working primarily with addictive behaviours. Whilst some of the basic principles of the model were relevant, I recall trying to 'force' my experiences of change into the model, 'tweaking' them in-order to 'fit'.

For me, these difficulties highlighted the dangers attached to adopting a more structured approach within assessment and therapy. For example, a new trainee may feel under pressure to formulate a client’s difficulties within a certain theoretical approach (out of a desire to create a competent impression to their supervisor, who is ultimately evaluating them).
approach may reflect that of one's supervisor, or alternatively the teaching received on the course. Here, just as my own personal experiences did not appear to fit with the Transtheoretical model, there is a danger the theoretical approach taken may not explain the client's difficulties, ultimately leading to an inappropriate targeting of therapeutic resources.

As the PBL progressed it became clear that the experience of the defined period of transition varied widely across group members and was influenced by a number of different social, personal and family/cultural factors within our lives at that time. As discussed, I found that my experiences of change were not adequately explained by the model adopted, failing to fit into the 'five stages' and being influenced by factors not included in the model.

As I struggled to 'fit' my own experiences into the model I began to lose motivation for the task at hand as I did not feel that it was relevant to my own experience of change. Initially I felt reluctant to discuss these difficulties with the rest of the group, fearing that perhaps I had not understood the model correctly.

Since beginning my placement and reflecting on the PBL, I have become aware that just as I felt anxious to please my new colleagues within the group by attempting to 'fit' my experiences to the model, there is a risk that the client may also feel pressured to 'fit' their experiences into the model adopted by the clinician.

For example, I am currently working with a client who initially presented with agoraphobic symptoms. However, during assessment, it became clear that her anxieties did not 'fit' into the typical conceptualisation of agoraphobia, rather her reluctance to leave the house was driven by social anxieties.

Had I attempted to force her experiences into a model of agoraphobia without acknowledging her individual experiences rooted in social anxieties it is unlikely that her perception of the formulation I had presented would have 'fitted' with her experiences.

Just as my motivation to engage in the PBL dropped when I felt my own different experience of change was not explained by the model, similarly, I believe engagement in therapy will ultimately reduce when the client feels that the formulation does not fit their experiences.

When working in a cognitive-behavioural approach, there is a risk that where these differences are not acknowledged and explored, the client may have trouble providing logs of
situations, thoughts and behaviours that fit with the clinician's conceptualisation of their difficulties.

My experience within the PBL has highlighted that if motivation and engagement in therapy are to occur, it is essential that a therapeutic environment exists whereby these differences in experience can be openly discussed. For me, feeling able to discuss my difficulties with the rest of the group was crucial to maintaining my motivation throughout the PBL exercise.

Reflecting upon my experience of the PBL and my subsequent awareness of the dangers attached to 'fitting the model to the client', I began to think about how organisational confines may lead to pressures to adopt certain therapeutic approaches.

I am currently working (in part) within a primary care setting where clients are offered time-limited cognitive-behavioural therapy. I began to wonder what happened to clients with slightly more severe difficulties, where 6 sessions of CBT may not be appropriate. These clients may fail to reach the criteria for a severe and enduring mental health problem and would therefore be unable to access secondary care input. I subsequently became aware of an ethical quandary whereby the clinician faces the dilemma of whether to 'fit the client's difficulties' to the organisationally defined mode of treatment, or risk leaving them without any input at all.

Since beginning my placement, I have discussed my thoughts with my primary care supervisor, who acknowledged these concerns as a real dilemma faced by Clinical Psychologists working within primary care sectors of the NHS to which there is no clear-cut answer.

**Reflections on the Theory**

During the final presentation, our group emphasised a number of factors rooted in the model, which encourage therapeutic change including increased social support and helping the client to see the advantages of changing.

I was fortunate in that my placement supervisor was able to attend the final PBL presentation, following which she commented that our approach was somewhat simplistic and that the realities of engendering therapeutic change when working with severe and enduring client populations were far more complex than the model suggests. I have to admit that after
undertaking quite an intense and anxiety-provoking six weeks, I found this response a little dispiriting!

However, with hindsight, I feel that I began the training course with a somewhat naïve understanding of ‘change’, whereby I viewed it as a solely positive experience and assumed that adults sought therapy ‘wanting to change’.

These views have shifted as my placement has progressed. Primarily, I have observed that whilst changing a negative health/addictive behaviour may have direct positive influences in terms of the client’s physical health, for some clients experiencing severe and enduring mental health problems, change is not always positive and the advantages may be stacked against the costs. Although clients may want help, this is not necessarily synonymous with wanting to change.

For example, the socially anxious client discussed previously had managed her anxieties over many years by never leaving home without her partner. During the initial assessment, the client appeared to recognise the benefits of entering therapy to increase her independence. However, it soon became apparent that she was unwilling to contemplate undertaking behavioural experiments and ‘home-work’. After exploring these difficulties together, she disclosed that her partner had admitted he no longer wanted to be part of the relationship and would leave her as soon as he was not needed to ‘look after her’.

For this client, attempting to ‘change’ was associated with an increase in independence, which clearly signalled the impending breakdown of her relationship. This, for her, far outweighed the benefits of change at that time and acknowledging and integrating these difficulties within the formulation was crucial to maintaining her engagement in therapy.

In summary, I recognise our approach to the PBL exercise was rooted in attempts to reduce our own anxieties concerning the task, rather than a more creative exploration of ‘The Relationship to Change’. Whilst less structured approaches would have yielded different reflections possibly allowing greater scope for creativity, had our approach been different, I would not have become aware of several important issues.

Primarily, the PBL process has helped me acknowledge anxieties underlying my need for guidance/structure within clinical practice. Although I feel these anxieties are still present, my awareness of them enables me to reflect upon them within future supervision. Similarly, I
have become aware of the risks attached to attempts to 'fit the client to the model' driven by these anxieties along with the ethical dilemmas attached to organisational confines on the structure of therapy.

Furthermore, I feel that our group approach to the PBL was vital in shifting my rather naïve perspective that 'change is always for the good' and that 'all clients want to change'. This has greatly impacted on my attitude toward assessment and I now endeavour to explore the possible negative impacts of change for the client.

I cannot comment on whether the approach taken by my PBL group was 'wrong' and will never know the reflections more creative approaches may have yielded. However, the process of writing this reflective account has encouraged me to approach future PBL exercises with a more creative stance, enabling me to reflect on the learning opportunities created.

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PROBLEM BASED LEARNING ACCOUNT:

YEAR 2

Year 2: March 2006
INTRODUCTION

In September 2005, Clinical Psychology trainees were presented with their second ‘Problem Based Learning’ (PBL) exercise\(^1\). The exercise aimed to provide space to utilise skills fostered during the first year of our\(^2\) training in addressing a ‘problem’ pertinent to our child/learning disability placements. To facilitate co-operative working and reflection, we were asked to address this ‘problem’ over three two-hour sessions within our Case Discussion Groups (CDG’s), before presenting our findings to the rest of the cohort. Finally, after six months on placement, we were asked to submit a reflective account summarising our experiences.

This work presents my reflections on this second PBL exercise. It opens with an overview of the ‘problem’, before summarising the approach taken by my CDG, highlighting differences from the approach taken within the previous year’s PBL. I then reflect on factors important in shaping our approach and the impact of the exercise on my Learning Disability (LD) placement. Specifically, I focus on decision-making processes and the toleration of uncertainty within my work, using reflections from my placement to inform an alternative explanation for the approach taken by my group. I conclude with a critique of the group’s approach, outlining future learning needs in preparation for my forthcoming child placement.

The Problem

We were asked to consider the hypothetical case of Mr and Mrs Stride, whose twins Sally and Sarah had been placed in short-term foster care, after being deemed at risk of emotional abuse/neglect by their parents. The Local Authority wanted to place them for permanent adoption, in the belief that Mr and Mrs Stride could not care for them. We were asked to assume the role of qualified Clinical Psychologists undertaking a joint instruction assessing the degree of risk to the children and, if necessary, developing a rehabilitation plan. Additional background information was presented pertaining to the family’s socio-economic status, support networks and cognitive abilities. Finally we were presented with the question: ‘Whose problem is it and why?’

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\(^1\) The first took place a year previously.
\(^2\) Due to the reflective nature of this account I will, where appropriate, write in the first person.
Reactions to the Task
On discussing the problem outline, I initially felt quite overwhelmed by the task’s restricted timescale, the complexity of the Stride’s circumstances and anxieties about whether I would become involved in similar legal processes once qualified. The group shared these uncertainties; specifically we found the potential finality associated with our recommendations (i.e. splitting the family) and the risk of making the ‘wrong decision’ particularly unsettling. Consequently, we began by researched the role of psychology within child-protection proceedings, before considering the psychological impact of: suffering childhood emotional/physical abuse; witnessing domestic violence and being removed from the family at a young age. However, the more we researched, the harder it was to reach any decision about the family’s future. Our indecision grew as we discussed the complexity of defining ‘good enough’ parenting (Winnicott, 1989) and the impact of learning difficulties/disabilities and socio-economic factors on ascertaining whether these skills could be fostered. Without actually undertaking an assessment in these areas, we concluded that it would be inappropriate to decide whether the children should stay with their parents. Thus our final presentation, rather than attempting to create certainty out of an uncertain situation, highlighted our emotional reactions to the PBL task and questions elicited through considering the problem.

Initial Reflections on Our Approach
In reflecting upon our approach, I found myself comparing it with that taken within last year’s PBL exercise. In reading my first PBL reflective account, I noticed that the group experienced similar anxieties about ‘getting it right’ and deciding where to begin. However, our reactions to these feelings differed across the two years. In the previous exercise, we reacted by attempting to find a ‘solution’ to the task ‘The Relationship to Change’ by utilising specific psychological theories. Conversely, within the most recent exercise, we reflected on our uncertainties, highlighting complexities to be considered if undertaking this assessment ‘for real’.

In considering possible explanations for these differences, I noticed that, in contrast to the abstract nature of the first PBL task, the second exercise lent itself to a definitive yes/no answer. Furthermore, the implications of such a decision, although hypothetical, hailed life-changing consequences for the Strides. I subsequently considered the work of Menzies (1959)13, within which social systems are hypothesised to function as a defence against anxiety within healthcare settings. Menzies’ suggestion that anxiety increases when making

13 Discovered in reading around a recent essay title.
decisions about the treatment/welfare of our ‘patients’ led me to wonder whether our reluctance to seek an ‘answer’ was an attempt to avoid reaching a decision about the Stride family, thus reducing collective anxieties about the consequences of making the ‘wrong’ decision. I also wondered if the hypothetical consequences were magnified by our experiences on placement and I noticed that uncertainties surrounding the risk of child abuse were emphasised to a greater extent by those undertaking child placements, whilst those of us on learning disability placements voiced uncertainty regarding the needs/abilities of the parents. I was subsequently keen to observe whether my thoughts on our approach would change as I progressed through my placement.

Changes on Placement
On beginning my placement I immediately noticed that I was working differently. My awareness of these changes was facilitated through reflecting on my previous Adult Mental Health Placement. There, I recalled feeling very responsible for the welfare of my clients and thus pressured to complete assessments/decide on my intervention quickly. Conversely, on my current placement, I appeared better able to embrace uncertainties about how/when/whether to intervene, using them in considering the complexities attached to my client’s circumstances and, if necessary, undertaking extended assessments. I also noticed changes in my formulations/intervention plans, within which I gave greater consideration to the interaction between the individual and their wider system. I used pathologising labels such as ‘depression’ or ‘anxiety’ far less and whilst my primary theoretical orientation was still cognitive-behavioural, I became less reliant on pre-existing intervention models for specific diagnoses, adopting a more flexible approach whereby my basic knowledge of CBT was adapted in constructing individualised treatment plans.

Impact of Placement Experience on PBL Reflections
In observing these changes alongside my experience of the two PBL exercises, I considered an alternative explanation for our approach to the second task. Specifically I considered whether it reflected a more global developmental progression in our learning related to a growing acceptance of ‘uncertainty’ within our work. If, procedures/structures within healthcare settings reduce anxiety associated with making important decisions (Menzies, 1959), perhaps my previous use of diagnostic/pathologising labels and pre-defined structured treatment packages served to reduce personal anxieties about being responsible for making the ‘right decision’ through leading me toward government guidelines (e.g. Department of Health, 2005) and formalised treatment approaches within which the ‘right’ course of action is clearly defined. Consequently, I wondered whether recent changes in my practice, alongside our more
flexible approach to the second PBL task, represented an acceptance that uncertainty surrounding our decisions cannot be evaded and that tolerating such uncertainty is necessary in order to facilitate more comprehensive assessments and thus more effective/individualised and less prescriptive intervention plans.

Impact of the wider context on the toleration of uncertainty

Of course it is important to consider that differences between placement contexts may also have informed these changes. For example, in contrast to Learning Disability services, where professionals often work with many individuals within the client’s system (possibly due to difficulties in self-expression among this population rendering it necessary to seek additional information from those involved in the client’s care.), Community Mental Health Teams (CMHT’s) predominantly work with their clients in comparative isolation. Consequently, I wondered whether the potential negative consequences of ‘uncertainty’ (with regards to whether an individual is at risk of self-harm) are greater within a CMHT setting, leading to pressure (within ourselves, or from others in the team) to ‘assess’ an individual’s problems and begin intervening quickly. This sense of urgency may be exacerbated if individuals are referred into the team with a pre-existing ‘diagnosis’ e.g. ‘depression’, leading us to make assumptions about their experiences in order to ‘fit them’ into a pre-existing model consistent with their diagnosis/governmental guidelines governing treatment of that diagnosis.

Conversely, within learning disability services there is an absence of formal guidelines/National Service Frameworks governing the ‘diagnosis’ and treatment of specific ‘problems’. This difference, combined with the differing nature of ‘risks’ encountered within these services, may result in professionals receiving referrals for more general concerns (e.g. ‘John has been reluctant to go the Day Centre’). This in turn, facilitates a culture whereby the necessity of more lengthy/context based assessments are accepted, reducing pressures to intervene immediately.

Final reflections on the PBL

Whilst the surrounding context has undoubtedly influenced my work, I believe that the transitions observed (both within my placement and during the PBL) are also reflective of a shift in my understanding of uncertainty and growing confidence in my ability to make decisions. Although the contexts differ between Learning Disability and CMHT services,

14 With the exception of challenging behaviour guidelines, Ball, Bush & Emerson (2004).
15 In Learning Disability services self-injurious behaviour is more often (although not always) conceptualised as an attempt to communicate distress, as opposed to an indicator of suicidal intent. Risk assessment may also involve more chronic risks related to health, entering relationships, parenting ability (Sellers, 2002).
there are times when similar pressures exist. For example, on my current placement I worked with a young man (living relatively independently) referred for ‘anger management’. Here a label had already been attached to his behaviour and there was pressure from other members of the team to complete my intervention, allowing their work with the client to begin. Following an initial assessment, I felt uncertain about the true nature and complexities of the client’s difficulties and chose to undertake an extended assessment, during which he disclosed feeling very ‘low’ and also told me that he had been engaging in serious risk taking behaviours. On this occasion, despite being exposed to similar pressures as those experienced within the CMHT environment, I was able to tolerate my own uncertainty about how best to intervene in order to facilitate an extended assessment, further exploring the complexity and level of my client’s distress.

**SUMMARY AND CONCLUSIONS**

Throughout this account, I have considered various explanations for our group’s reluctance to reach an answer about the future of the Stride family. Initially, I wondered whether this choice had represented our attempts to reduce anxiety associated with making such an important decision and I was aware that attempting to reach a decision may have allowed us to become more familiar with the role of the psychologist in child protection proceedings/parenting assessments. However, since reflecting on my own placement experiences, I now wonder whether our approach represented a developmental shift relating to the toleration of uncertainty. In considering this possibility, I remain mindful that other members of my group (interestingly those on child placements) hold different opinions on our approach, more consistent with my earlier discussions about anxiety associated with the consequences of making important decisions. I am also aware that my own opinion is likely to have been shaped by a growing confidence within my work, which has in turn, been related to my placement supervisor’s efforts to guide me toward making my own decisions, rather than providing me with answers herself. Consistent with this, Menzies suggests, it is only by experiencing the anxiety associated with making decisions that we become more confident in our capacity to tolerate anxiety linked to our work.

In the light of my impending Child Placement, it will be interesting to see whether my opinion on the group’s approach is maintained. Specifically, I wonder if being exposed to the possible impacts of emotional/physical neglect and domestic violence on children within my child placement will make it more difficult to tolerate uncertainty of the type outlined within the PBL. This may account for the differing reflections of those group members currently on
their child placements. As such, it will be interesting to consider whether my opinions on our approach will change as the potential consequences of making decisions are magnified through working in closer proximity with children. Similarly, it will be interesting to note whether my ability to tolerate uncertainty is reduced by virtue of my assumptions about the 'vulnerability of children' and I am keen to notice whether this leads to a resurgence of my efforts to seek containment from my supervisor when 'making decisions'.

REFERENCES


PROBLEM BASED LEARNING ACCOUNT:

YEAR 3

Year 3: February 2007
INTRODUCTION

In September 2006, a cohort of trainee Clinical Psychologists were presented with their third ‘Problem Based Learning’ (PBL) exercise; an initiative aiming to provide opportunities for reflective practice and collaborative learning, devised during the cohort’s first year of training. Working within our usual Case Discussion Groups (CDG’s), we were encouraged to consider a ‘problem’ pertinent to our impending ‘Older Adult’ placement. We then presented our ‘findings’ to the cohort, before writing a reflective account considering our approach in the light of subsequent placement experiences.

For our cohort, this final task represented the culmination of three PBL experiences. Consequently in writing this account, we are in the position to reflect upon our response to the current task alongside continuities/shifts from those taken previously. Thus, my account will adopt a developmental perspective\(^\text{16}\), beginning with an overview of the task, before summarising and comparing my group’s response across previous tasks. Focussing on issues of process, rather than content, I shall then consider the nature of our approach in the light of subsequent placement experiences, emphasising related personal and professional learning, before considering ways in which the group can develop this learning as we head towards qualification.

The Problem

Our task centred on ‘Mr Khan’, a 72 year-old, recently widowed gentleman of Muslim faith, who migrated to England from Pakistan during his thirties. Mr Khan’s youngest daughter ‘Maya’ had recently contacted social services expressing concerns about her father’s deteriorating memory/self-care skills. Information on Mr Khan’s family and background was also provided, including reference to his: elder daughter Shazia (currently living in Pakistan); previous conflicts with the local religious community (following their response to his wife’s death), and historical conflicts with Maya, whom he disowned following her decision to marry a European. Finally we were presented with a list of prompts focussing on various factors to be considered in working with Mr Khan.

Reaction to the Task

After reading the vignette, there was a collective sigh within our group, paired with an open expression of frustration regarding the wider demands currently facing us on training. It

\(^{16}\) I have chosen this approach throughout my reflective accounts, primarily because I find it useful for my own learning but also to provide some continuity and flow when I may return to my work in the future.
seemed as if the PBL task was ‘the final straw’ leading us to feel overwhelmed by numerous co-existing pressures. However, after several comments about “where to begin” our facilitator encouraged us to consider what we would do if meeting Mr Khan within our clinical role. We then responded by trying to gain a clearer definition of the ‘problem’, which we decided to be an issue of ‘diagnosis’. In addressing this issue, we chose to balance wider pressures by undertaking a ‘good enough’ presentation, which could be comprised quickly and efficiently with a minimum of additional stress. Consequently, we worked mostly in isolation, researching issues associated with a differential diagnoses in older people. For our presentation we each stated the ‘hypothetical’ case for whether Mr Khan’s difficulties were best explained by ‘dementia’, ‘depression’, ‘bereavement’ or ‘normal ageing’ which, whilst acknowledging the impact of cultural issues upon the assessment, focussed predominantly upon ‘diagnosis’.

**Initial Reflections on Our Approach**

As the task progressed, we were aware that our group had adopted a different format from the more collaborative and creative approaches being undertaken by other groups. This was interesting given that our response to the second PBL task had comprised a move away from the focus on certainty (dominating our approach in Year 1) toward a more creative presentation, less focussed on ‘getting it right’. At the time, I linked such changes to our growing ability to tolerate ‘uncertainty’ within our work. Consequently, I looked back on our current ‘rigidity’, with some surprise.

However, I felt our current response seemed different from that of year 1, reflecting a certain dismissive attitude toward the current task – possibly evidenced by our collective feeling that we had not ‘got to know’ Mr Khan in the same way as we had the ‘Stride’ family during last year’s PBL task - as opposed to a desire to ‘get things right’. At the time, we were reluctant to acknowledge this, comparing our response to the realistic need for ‘good enough’ working in light of competing NHS pressures. Yet it was interesting that a marker of our final presentation expressed disappointment at letting these ‘pressures’ stifle our passion for the task, leading me to wonder why we had responded so differently to this task; something I have considered further across the course of my placement.
Experiences on Placement

Medicalised context
My first impression of the placement was the highly ‘medicalised’ nature of the service. Psychologists tended to work in isolation, letters were rarely copied to ‘patients’\footnote{In quoting this term I am emphasising the tendency to refer to people utilising the service as ‘patients’ as opposed to clients, service users or individuals.} and, as evidenced during a team discussion of a referral for a gentleman with hoarding difficulties, ‘therapeutic’ input gave little consideration to associated psychological factors; the referral being passed first to a social worker to arrange for a ‘cleansing’ of the house and subsequently to a CPN for management of physical health issues.

Placement shock
However, as the placement progressed, these initial impressions were quickly subsumed by my personal reactions. As someone who has had little personal contact with older people (my grandparents having died, 3 before my birth), the PBL task and placement experiences presented me with my first prolonged exposure to older people for some time and raised some difficult feelings for me. For example, on one occasion as I visited a locked dementia ward, I recalled trying to distract myself from my own feelings of distress, elicited by the distant sounds of an agitated woman banging on the locked door in an effort to get out. Initially, I felt uncomfortable that I had distracted myself rather than attempting to resolve the situation (by seeking staff support for the individual) and responded by trying to forget the incident. However, as time passed I experienced further emotional reactions to the placement context which I was less able to ignore, namely an acute awareness of the mortality of myself and my parents.

Discussions with colleagues
In discussing my feelings with other team members, I found it interesting to reflect upon their responses, recalling how one member of staff told me “to deal with it...you must remind yourself that you’re different...you’re not like them... you may have felt sad or worried but you’ve never been so unable to cope that you were\textit{ depressed}”. Initially I found these comments\ really strange, feeling like I had entered a parallel universe where the teachings of training were no longer relevant. I also found it difficult to ignore my feelings and soon noticed their impact upon my clinical work.
Difficulties in Therapeutic Work
These feelings were most pronounced, when working with Mary, an eighty-eight year old lady suffering from feelings of anxiety and low mood following a serious fall. Her husband and only son had both died and her family lived far away, never visiting or calling. During our initial sessions, I often tried to push my feelings of sadness elicited by her situation aside, focussing instead on structured session plans and treatment goals, possibly through some effort to elicit speedy change, thus resolving both Mary’s and my own feelings of distress. Interestingly this seemed to be accompanied by Mary’s increasing protestations of hopelessness about the prospect of change. Only when I allowed myself to engage with both of our feelings of hopelessness and distress through supervision, were we able to break out of this cycle by identifying avenues for small, achievable changes within her current context.

Subsequent Reflections on the PBL Process
In reflecting upon both placement PBL experiences within our CDG, I re-considered the role of organisational procedures/structures in distancing professionals from anxiety associated with clinical decision-making (Menzies, 1959). I had discussed this issue within previous reflective accounts and wondered whether ‘routinised’ treatments within older people’s services (including my own session plans) served a similar anxiety-reducing role. However, in considering this, I wondered why such practices seemed more pronounced in older people’s services. In doing so, I acknowledged our initial reflections on the PBL task, i.e. that there is a need for ‘good enough’ working in the light of external pressures. Indeed, this may reflect something of the wider pressures facing clinical psychologists within services for older people, where both posts and willing applicants are sparse (Britton & Woods, 1999). This may in turn contribute to the seemingly isolated nature of psychological input and lack of psychological awareness observed on my current placement.

However, I could not help but reflect upon the similarities between the ‘medicalised’, ‘dismissive’ and disjointed nature of therapeutic provision on placement and our group’s response to the PBL task. This led to a consideration of wider societal ‘ageist’ attitudes. These have been defined as a deep seated uneasiness towards the aging process on the part of the young and middle aged (Butler, 1969) and more latterly (within Kitwood’s ‘malignant social psychology’, 1997) as unconscious attempts to avoid anxiety associated with growing old, by projecting negative attributes such as dependency and helplessness onto the ageing population.
In considering this, I recalled how, alongside my own limited contact with older people, several other group members had parents or grandparents who were ill at the time of the PBL task. Consequently, I wondered whether for our group, the task had captured our unease in confronting very real personal concerns about the consequences of aging for us and our families. As such, it is possible that avoiding discussion of more complex cultural, familial and contextual issues served to dehumanise Mr Khan, keeping him at a ‘safe distance’ and thus protecting us from personal anxieties about getting older.

SUMMARY AND CONCLUSIONS

In considering our group’s approach to this final PBL task, I have considered a number of possible explanations. In particular, I focussed on attempts to avoid distress elicited by working with older people, a hypothesis informed by my own personal reactions on placement. However, it is also important to acknowledge alternative perspectives. Specifically, one group member suggested that our limited cultural diversity may have rendered us overwhelmed by the apparent ‘complexity’ of the task and thus reluctant to engage with cultural issues on a deeper level. Another group member argued the need for acknowledgement of older peoples’ physical health vulnerabilities, which may necessitate more ‘medicalised’ approaches to service provision.

However, I believe we must also guard against relying on ‘routinised’ or ‘medical’ approaches as a means of distancing ourselves from the inevitability of life and death. Whilst I acknowledge that this explanation may not sit easily with all, I hope that my account has demonstrated that ignoring this possibility and avoiding our own feelings through attempts to become a ‘superpsychologist’ (Britton & Woods, 1999) is unhelpful. Consequently, I believe that acknowledging susceptibility to such pressures is the first step towards combating them. In light of this, I now wonder whether engagement with, and exploration of, the sudden feelings of being overwhelmed in response to the task, may have freed us toward approaching the task at a different level. Whilst I am encouraged that the CDG provided us with a forum for reflecting upon these issues in the light of placement experience - indeed it was noticeable that our meetings across this placement were associated with more anguish than any other - I wonder if it is enough to reflect upon these issues in a separate context.

As clinical psychologists we are encouraged to ‘step off the fence’, initiating systemic change and challenging outdated practices. Consequently, I wonder if our group should continue to explore ways in which we can begin to work towards changing things we find distressing or
unacceptable. This may feel like a huge task, particularly for trainees who are often only working within a service for a short period. However, just as my supervisor recently reported feeling refreshed by my 'non-pathologising' letters, it is important to remember that changes can be subtle and that challenging acceptance of the status quo (across any setting) is necessary in addressing wider discourses about hopelessness and inability to change systemic practices, just as it is within our clinical work.

REFERENCES


CASE DISCUSSION GROUP (CDG)
PROCESS ACCOUNT (YEAR 1)

"Reflections on the CDG Process across the First Year of Training"

Year 2: September 2005
SUMMARY OF CASE DISCUSSION GROUP PROCESS ACCOUNT (YEAR 1)

From October 2004, as part of a new initiative aiming to promote theory practice links through peer support/learning, Clinical Psychology trainees were required to participate within case discussion groups (CDG’s). These consisted of fortnightly meetings between 5-6 trainees and a facilitator, culminating in the writing of an individual reflective account, summarising experiences across the duration of the year.

As such, during this first account, I considered my own CDG experience across my first year of training. In doing so, I reflected upon my group’s initial feelings of frustration towards our facilitator (following her passive, facilitative - as opposed to ‘expert’ - role), which gradually diminished across the year. These experiences were then considered alongside relevant psychodynamic theories as I identified our progression through different stages of group process. Specifically, I considered whether our resultant capacity to function without explicit guidance may have reflected reduced dependency upon our facilitator. I subsequently considered my experience of presenting a case to the CDG, during which the group became a forum for intra-group learning, allowing me to benefit from hearing other about ways in which other group members had dealt with similar experiences.

In concluding the account I went on to consider the implications of my CDG experiences for my therapeutic work, with regards to the way in which avoidance of the ‘expert’ position within Cognitive Behavioural Therapeutic approaches may also generate uncertainty/frustration for my clients. Finally, I considered the extent to which the group’s frustration with our facilitator’s decision not to impart knowledge/expertise may also have represented wider developmental concerns about ‘getting things right’/being evaluated within our first year of training.
CASE DISCUSSION GROUP (CDG) 
PROCESS ACCOUNT (YEAR 2) 

“Reflections on the CDG Process across the Second Year of Training”

Year 3: July 2006
SUMMARY OF CASE DISCUSSION GROUP PROCESS ACCOUNT (YEAR 2)

Following on from the Case Discussion Group (CDG) reflective account written at the end of my first year of training, this second account summarised my experiences across the second year within the CDG. Here, the group welcomed a new facilitator, whilst wider placement contexts also shifted from Adult Mental Health to Child and People with Learning Disability placements.

In writing the account, I adopted a developmental framework and, consistent with my emerging interest in narrative therapy, the account was structured through use of nautical metaphors (‘taking the helm’/ ‘learning the ropes’) pertaining to key transitions across the year. Here, the specific focus of the account was on negotiations with regards to the set up of the group and the way in which attempts to ‘take charge’ seemed to shift between us and our facilitator. In doing so, I drew attention to re-emerging feelings of frustration within the group towards our facilitator’s attempts to ‘take charge’ of the group process. Here, I noted the way in which the group were able to resolve their frustrations in a more open and constructive manner than the previous year. This shift was then considered in relation to psychodynamic and systemic theories of change, before observing the ensuing move towards more creative and reflective discussions of personal/professional issues.

In concluding, I considered the extent to which this more relaxed/integrative focus may also have reflected both the group’s developmental transition through the training course, alongside the wider placement context and more creative ways of working with children/people with learning disabilities. Finally, I drew attention to ways in which the group could continue to learn from these experiences in light of the predicted re-emergence of concerns about ‘getting it right’ as we progressed towards qualification.
RESEARCH DOSSIER

This section of the portfolio contains evidence of research undertaken throughout the training course, including a Service Related Research Project (SRRP) undertaken during the adult mental health placement; a summary of a group piece of qualitative research undertaken in year two; a major research project completed in the third year and a record of research experience presented in the form of a research logbook.
SERVICE RELATED RESEARCH PROJECT

“An Audit of the Supervision and CPD Activities of Clinical and Counselling Psychologists Working within an NHS Trust”

Year 1: July 2005
ACKNOWLEDGEMENTS

I would like to thank all Counselling and Clinical Psychologists who participated in the above study; their honest responses have been invaluable in ascertaining an accurate evaluation of supervision and Continuing Professional Development activities within the Trust. In addition, I would like to thank my placement supervisor and the Trust Director of Psychological Therapies, for permitting me to undertake this project and providing valuable guidance, support and feedback throughout.

I would also like to thank the departmental secretary for anonymising the data before handing it to me for entry and finally, the Trust Audit Team, for allowing me to expand upon their previous audits.
Audit of the Supervision and CPD Activities of Clinical and Counselling Psychologists Working within an NHS Trust
ABSTRACT

Objectives: In the context of amendments in BPS re-registration criteria, to explore the level, nature, funding, organisation and barriers preventing, supervision and continuing professional development (CPD) activities, amongst NHS chartered psychologists.

Method: In consultation with Trust Directors, a questionnaire exploring these issues was designed and distributed to all clinical and counselling psychologists (n=33), employed within the Psychological Therapies department of an NHS Trust.

Results: The majority of supervision (77%) and CPD (72%) was Trust financed and result suggest that large proportions of counselling (100%) and clinical (75%-87.5%) psychologists currently meet divisional requirements.

With regard to CPD, a substantial proportion of (primarily clinical) psychologists (46%) failed to meet BPS criteria. However, high levels of missing data limited the ability to draw firm conclusions from these findings.

Improvements were observed (following previous audits) in CPD and supervision organisation, evident in the use of supervision and CPD to address a range of outcomes. Furthermore, percentages of respondents recording outcomes following supervision (91%), receiving annual appraisals (63.6%), utilising Performance Development Plans (59.1%) and systematically organising CPD activities (45.5%) compared favourably with previous audits and other studies.

Limited financial support from the Trust and time constrains were observed to be the primary barriers hindering CPD access, although levels of missing data questioned whether these perceptions were representative of the entire sample.

Conclusions: Whilst substantial improvements CPD/supervision organisation and nature are observed, further exploration is necessary to explore whether BPS re-registration criteria for CPD are being met.
1. INTRODUCTION

Striving toward the attainment of professional and service requirements identified within the National Health Service (NHS) priorities and National Service Frameworks (Department of Health, 1999), current National and regional NHS clinical governance agendas increasingly emphasise ‘lifelong learning’ and ‘professional development’; requiring employees to demonstrate undertaking systematic ‘lifelong learning’ or continuing professional development (CPD).


Divisional requirements for CPD vary, practising clinical and counselling psychologists must currently undertake 70 hours and 40 hours CPD (annually) respectively (Division of Clinical Psychology [DCP], 2001b, Division of Counselling Psychology [DcoP], 1999). Relevant activities include all post-qualification training along with in-house activities (e.g. research, teaching, reading), the exact composition varying according to development needs.

The DCP (2001b) and DOH (1999) propose that ‘learning needs’ (areas of development required to fulfil personal professional/service objectives) be identified within Individual Performance Reviews (IPRs) and formalised within Personal Development Plans (PDPs).

Identified needs are prioritised during supervision, before selecting and implementing appropriate development activities (DCP, 2001b). Completed activities are formally logged (BPS, 2004) before reflecting upon whether learning needs have been met, though ongoing supervision and IPRs (DCP, 2001b).

Supervision, both giving and receiving, are defined as ‘in-house’ CPD activities. Counselling psychologists must undertake a minimum of 90 minutes supervision monthly, whilst clinical psychologists must undertake a minimum of 60-90 minutes, per 20 sessions worked (DCP, 2001a DCoP, 2005). Content should address a range of core outcomes, defined within the Key Roles of the National Occupational Standards (NOS) for applied Psychologists, including: ethics; practice; communication; research and development and, where applicable, training and management issues (BPS, 2004).
Whilst research suggests that clinical and counselling psychologists value and utilise CPD and supervision, variability is observed regarding level, organisation and monitoring (Golding, 2003). Previous supervision and CPD audits of clinical psychologists within this Trust, established that only 51.7% received above 1.5 hours supervision (monthly), 54.2% were not appraised annually and 76.4% lacked a PDP, most reporting informal approaches to CPD organisation and monitoring.

Audits in North-West England also observed that time constraints and limited organisational funding, were frequently cited barriers to accessing CPD (Golding, 2003).

From September 2005, in addition to mandatory supervision requirements, continuing registration of all chartered psychologists holding a practising certificate will depend upon submission of formal CPD logs. These will be used to assess the level, content and organisation of CPD.

In order to target resources toward areas of need, Directors of this Trust commissioned an audit exploring the extent to which chartered clinical and counselling psychologists are meeting BPS supervision and CPD criteria. Objectives included exploration of the:

- extent to which chartered psychologists, are undertaking both CPD and supervision and the nature of activities undertaken;

- extent to which CPD is systematically planned toward meeting needs identified in IPRs and PDPs;

- extent to which supervision encompasses identification of learning needs, reflective practice and action planning;

- funding of supervision and CPD (i.e. Trust funded versus external/private sources);

- perceived barriers to accessing CPD.

Audit of the Supervision and CPD Activities of Clinical and Counselling Psychologists Working within an NHS Trust
2. METHODOLOGY

2.1: Design & Sample Population

All qualified clinical and counselling psychologists (n=33, 28 females 5 males) working within the Trust (10 B Grades, 23 A Grades) were invited to participate in a postal questionnaire surveying current CPD and supervision activities.

Mail-outs yielded an initial response rate of 66.6% (n=22) comparing favourably with similar studies (Golding, 2003); subsequent mail-outs failed increase response rate.

2.2: Procedure

Development of the Questionnaire

To maximise content validity, the questionnaire was developed in collaboration with senior Trust professionals, using previous audits (Unpublished SRRP, 2001, Appendix 5) to guide item development, thus ensuring comparability of results (for final questionnaire see Appendix 4).

Items pertaining to the level of supervision and CPD were adapted using BPS guidelines, from those originally piloted and developed by Gabbay et al, (1999).

To ascertain the funding (Trust/external e.g. private/self-funded/free) of CPD and supervision, along with whether BPS criteria were being reached, respondents were requested to list sessions worked for the Trust/elsewhere. These figures were used to calculate a target level of supervision necessary to cover sessions worked (see Appendix 9).

The questionnaire also explored CPD organisation, requesting respondents to endorse their primary method from one of several categories (systematic/ad-hoc). Categories were adapted, from those listed within a consultation document produced by the Department of Health Social Services and Public Safety Clinical Psychology Speciality Advisory Committee (2003), to explore whether respondents organised CPD toward meeting Trust/personal objectives.

Respondents were also requested to indicate whether each of the NOS core outcomes had been discussed within their past six supervision sessions and/or addressed within CPD (over
the last 12 months). Research, evaluation and supervision issues were included with these outcomes, following consultation with Trust Directors.

To ascertain any factors hindering CPD, respondents were asked to rank 7 potential barriers, adapted from those identified by Golding 2003 (Appendix 5), in order of importance. Barriers were adapted to include: lack of support from employers in allowing dedicated CPD time; lack of organisational support and personal commitments. Space was provided to encourage open-ended feedback, free from categorical constraints.

**Ensuring anonymity and questionnaire response procedure**

Preserving anonymity was considered critical in gaining honest, accurate responses. Whilst name, grade and base were logged (allowing respondent characteristics to be monitored), this data was detached, before transferring questionnaires to the researcher (covering letter, Appendix 6).

The mail-out package also included information regarding impending BPS statutory regulations, clarifying the rationale behind the survey and questionnaire items (Appendix 7).

**2.3: Data Analysis**

Data\(^{18}\) was analysed using SPSS for Windows (v11) and Microsoft Office Excel (2003). Thematic content analysis explored responses to qualitative feedback questions. Inter-rater reliability was obtained through a colleague, aware of the context surrounding the audit. Categorisation agreement was 91% (Kappa=0.88), indicating good inter-rater reliability (Appendix 14).

**3. RESULTS**

**3.1: Sample Demographics**

Of the 22 respondents (age range 24-59 years, see Table 4, Appendix 7), 21 were female, 11 (50%) were A Grade chartered psychologists and 6 identified themselves as chartered counselling psychologists.

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\(^{18}\) Data pertaining to provision of supervision, organisations providing CPD and IPR objectives is not presented due to word constraints, all data be included in feedback reports to Trust Directors.
All were members of the BPS, 72.7% \( (n=16) \) and 27.3% \( (n=6) \) holding chartered and affiliate membership status respectively.

Respondents were employed within a mixed urban-rural community, the majority \( (n=11) \) describing their theoretical orientation as cognitive behavioural\(^{19}\) (Figure 1) and working within adult mental health services (see Figure 9, Appendix 8 for frequencies).

Fourteen respondents (63.6%) worked 10 or less sessions (monthly) for the Trust, only 3 worked full-time (40 sessions). Little work was undertaken privately/other Trusts, those respondents undertaking such work \( (n=4) \), not exceeding 5 sessions per month (frequencies: Figure 8, Appendix 8).

**Figure 1: Primary Theoretical Orientation (Percentages & Frequencies of Respondents).**

3.2: Level of Supervision/CPD

3.2.1: Supervision

Items exploring the level of supervision, revealed 95.5% of respondents \( (n=21, 1=\text{missing}) \) received monthly supervision, 19 (86.4\(^{2}\)) and 20 (91%) undertaking equal to or above 90 and 60 minutes respectively (see Tables 5, Appendix 9 for frequencies).

\(^{19}\) Various combinations of orientations e.g. CBT & humanistic were included under the 'integrative' heading.

\(^{2}\) Unless otherwise stated, all reported percentages are of the total sample, as given the small sample, valid percentages may yield a falsely inflated/deflated impression of findings.

Audit of the Supervision and CPD Activities of Clinical and Counselling Psychologists
Working within an NHS Trust
With regard to divisional criteria, all counselling psychologists (100%, n=6) undertook 90 minutes supervision or more (monthly), whilst 87.5% (n=14) and 75% (n=12) of the 16 clinical psychologists, received 60 and 90 minutes supervision respectively (or more) per 20 sessions worked (for calculation formula: Appendix 9).

3.2.2: CPD

Whilst, CPD was universally undertaken, several respondents failed to list the number of hours undertaken. In addition, boxplot and frequency (Figures 10 & 11, Appendix 10) analysis of the level undertaken, identified several outliers, which were excluded before calculating means.

Subsequent, analysis of the means, revealed that although the mean level of CPD reported was 83.25 hours (n=16, SD=39.64). Only 45.5% (n=10) of respondents met BPS divisional requirements; 4 (66.7%) counselling (requirements= 40 hrs annually) and 6 (37.5%) clinical psychologists (70 hours CPD per annum).

3.3: Funding of Supervision/CPD

The majority of both supervision (77%) and CPD (72%) were Trust financed (Table 1). Seventeen respondents (77.3%), 15 undertaking no external/private work, accessed externally financed CPD.

<table>
<thead>
<tr>
<th>Supervision</th>
<th>No. Hours (%)</th>
<th>Total Hours</th>
</tr>
</thead>
<tbody>
<tr>
<td>Trust</td>
<td>76.5 (77%)</td>
<td>99.75</td>
</tr>
<tr>
<td>External</td>
<td>23 (23%)</td>
<td></td>
</tr>
<tr>
<td>CPD</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Trust</td>
<td>1276 (72%)</td>
<td>1772</td>
</tr>
<tr>
<td>External</td>
<td>496 (28%)</td>
<td></td>
</tr>
</tbody>
</table>

3.4: Content of Supervision/CPD

3.4.1: Supervision

The majority of respondents (n=19) accessed supervision individually, from senior professionals and supervision was used to address a range of issues (Figure 3), most commonly therapy and reflective practice, whilst discussion of teaching, research and
development issues was less common. Only 9 respondents accessed supervision within groups (for frequencies see Figure 13, Appendix 11), which subsequently contributed minimally to meeting BPS criteria, percentages presented in section 2, remaining unchanged regardless of increases in group size.

Figure 3: Issues Addressed During Last 6 Supervision Sessions.

![Bar chart showing issues addressed during last 6 supervision sessions.](chart.png)

Whilst clinical supervision was most popular (accessed by 21 respondents, 1, missing) and caseload supervision least utilised (Figure 4), 63.6% undertook supervision across all categories, only 2 respondents receiving clinical supervision alone (Figure 12, Appendix 10).
Figure 4: Percentages of Respondents Accessing Varieties of Supervision:

<table>
<thead>
<tr>
<th>Nature of Supervision</th>
<th>% of Respondents</th>
</tr>
</thead>
<tbody>
<tr>
<td>Clinical</td>
<td>95.5</td>
</tr>
<tr>
<td>Managerial/Org</td>
<td>77.3</td>
</tr>
<tr>
<td>Caseload</td>
<td>68.2</td>
</tr>
</tbody>
</table>

Sample N= 22
Valid N= 21

3.4.2: CPD

Results suggest that CPD activities were directed toward a range of outcomes (Figure 5), most commonly improving clinical practice (n=21) followed by training/management issues, while research and ethical issues, were least addressed.

Figure 5: Outcomes Targeted by CPD (last 12 months).

<table>
<thead>
<tr>
<th>Skills Targeted</th>
<th>% Respondents</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ethos</td>
<td>36.4</td>
</tr>
<tr>
<td>Therapy</td>
<td>36.3</td>
</tr>
<tr>
<td>R&amp;D</td>
<td>50</td>
</tr>
<tr>
<td>Training</td>
<td>68.2</td>
</tr>
<tr>
<td>Management</td>
<td>40.9</td>
</tr>
<tr>
<td>Personal Development</td>
<td>68.2</td>
</tr>
<tr>
<td>Supervision</td>
<td>59.1</td>
</tr>
</tbody>
</table>

N=22

Audit of the Supervision and CPD Activities of Clinical and Counselling Psychologists Working within an NHS Trust
A variety of in-house and external activities were undertaken, most frequently attending conferences (86.4%, n=19) and reading (95.5%, n=21); on which respondents spent an average of 23.9 (SD=19.4, n=22) and 22.5 (SD=14, n=21) hours (annually), see Table 2.

Least time was spent undertaking research and observation/mentoring and 45.55% (n=5) of those respondents undertaking research (n=11), reported undertaking no CPD toward improving their skills in this area.

Table 2: CPD Activities Undertaken Over Last 12 Months (Mean Hours Spent on Each).

<table>
<thead>
<tr>
<th>Activity</th>
<th>% of Total Sample Undertaking (N)</th>
<th>Mean Hours (SD)</th>
<th>Valid N for means*</th>
</tr>
</thead>
<tbody>
<tr>
<td>External Delivered</td>
<td>68.2 (15)</td>
<td>10.1 (12.6)</td>
<td>18</td>
</tr>
<tr>
<td>External Received</td>
<td>86.4 (19)</td>
<td>23.9 (19.4)</td>
<td>16</td>
</tr>
<tr>
<td>R &amp; D</td>
<td>50 (11)</td>
<td>4.5 (10.6)</td>
<td>15</td>
</tr>
<tr>
<td>Reading</td>
<td>95.5 (21)</td>
<td>22.5 (13.5)</td>
<td>13</td>
</tr>
<tr>
<td>Observing/Being Observed</td>
<td>22.7 (5)</td>
<td>1.2 (4.9)</td>
<td>17</td>
</tr>
<tr>
<td>Personal Therapy/Mentoring</td>
<td>45.5 (10)</td>
<td>4.4 (8)</td>
<td>17</td>
</tr>
</tbody>
</table>

*After removing missing data and outliers.

3.5: Organisation of Supervision/CPD

3.5.1: Supervision
Although 95.5% (n=21) of respondents undertook supervision at regular times, only 27.3% (n=6) held a supervision contract. Ninety-one percent (n=20) of respondents kept records following supervision; over half (n=13) recording reflective practice and action plans, while only 8 respondents recorded learning outcomes (Figure 6).

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20 After excluding outliers (see Appendix 12)
3.5.2: CPD

With regard to IPRs/PDPs, 14 respondents (63.6%) held PDPs, this figure slightly exceeded those receiving annual appraisals (n=13, 59.1%). Table 3, highlights that CPD organisation varied according to the source of funding, with Trust financed CPD most commonly planned toward meeting Trust objectives (45.5%), although several respondents adopted a mixture of both ad-hoc organisation and directing activities toward organisational and personal objectives.

With reference to externally financed CPD, several respondents continued to organise CPD toward meeting Trust objectives, although 54.5% of respondents failed to endorse any predominant organisational method.

Table 3: Predominant Method of CPD Organisation.

<table>
<thead>
<tr>
<th>CPD Organisation</th>
<th>Trust N (%)</th>
<th>External N (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ad-hoc</td>
<td>2 (9.1%)</td>
<td>0</td>
</tr>
<tr>
<td>Planned: Trust Objectives</td>
<td>10 (45.5%)</td>
<td>4 (18.2%)</td>
</tr>
<tr>
<td>Planned: Personal Objectives</td>
<td>0</td>
<td>2 (9.1%)</td>
</tr>
<tr>
<td>All of above</td>
<td>5 (22.7%)</td>
<td>2 (9.1%)</td>
</tr>
<tr>
<td>Planned: Trust &amp; Personal objectives</td>
<td>0</td>
<td>2 (9.1%)</td>
</tr>
<tr>
<td>None</td>
<td>5 (22.7%)</td>
<td>12 (54.5%)</td>
</tr>
</tbody>
</table>

Audit of the Supervision and CPD Activities of Clinical and Counselling Psychologists Working within an NHS Trust
3.6: Barriers to CPD

Whilst not all respondents rated each of the 7 barriers to CPD, the pressure of clinical work and lack of financial support from the organisation, were perceived as central barriers to CPD, achieving the highest mean ratings (1.8 and 2.8 respectively, where 1=most important barrier 7=least, see Figure 15, Appendix 13).

Eight respondents provided additional comments (Appendix 14), 3 reporting that time constraints hindered CPD; specific comments reflecting part-time staff members' difficulties obtaining time-off in lieu for CPD undertaken outside contracted hours and perceptions that clinical time lost through undertaking CPD must be recouped.

Four individuals reported a paucity of relevant CPD activities, comments reflecting perceptions that CPD opportunities lacked relevance to the professional level/speciality of respondents and were targeted toward other Trust employees.

Two respondents commented that they had experienced no difficulties/received good support in accessing CPD.

4. DISCUSSION

This audit represents an overview (findings being limited in the absence of more detailed exploration of selected issues) of CPD and supervision activities among chartered psychologists within an NHS Trust.

Given the good response rate (66.6%), results are assumed representative of the sample population, although the impact of the self-selecting nature of the study (individuals who felt more comfortable responding honestly), on positively skewing the data should be acknowledged.

The higher proportion of female respondents is also comparable with other studies (Golding, 3003, Knight & Llewelyn, 2001), while greater proportions of staff held BPS membership than previous studies had observed (Golding, 2003).
4.1: Level of Supervision/CPD

Results show that the proportion of clinical and counselling psychologists obtaining 90 minutes supervision or more had increased by 30% (to 86.4%), from figures identified within previous audits (57.1%), all counselling (n=6) and 87.5% of clinical psychologists (n=16) now meeting respective divisional criteria. Furthermore, 91% of respondents received regular supervision of 60 minutes or more, exceeding other audit findings (87.9%, Golding, 2003) and a testament to the efforts of respondents and Trust directors in raising the profile of supervision and CPD.

Whilst CPD remained universally undertaken, a substantial proportion of clinical psychologists (62.5%) failed to meet current DCP and re-registration criteria. Whilst these findings may represent an underestimate (several respondents failed to list hours spent undertaking CPD). Further investigation must explore this issue, acknowledging the alternative possibility that respondents may have felt less comfortable/motivated in answering honestly due to fears surrounding their competency in these areas.

A further possibility relates to weaknesses in questionnaire design, some respondents may have felt unable to dedicate necessary time to responding accurately to such a lengthy questionnaire. As such, future audits may wish to focus solely on collecting data in this area, increasing motivation to respond accurately.

4.2: Content

Whilst caseload supervision was least utilised, it was encouraging to note that only a small percentage of the sample (9.1%) received clinical supervision alone and, in addition to discussing clinical issues, supervision content addressed a range of NOS core outcomes, although discussion of policy (40.9%), research (68.2%) and diversity issues (50%) were less common.

These findings were echoed across CPD content, which, whilst directed toward a variety of areas, less frequently addressed research/ethical issues, even when respondents undertook research within their work.

Whilst these findings suggest expansion in the breadth of issues addressed within CPD/supervision, room remains for further improvement. Such improvements may be
facilitated by increasing the profile of supervision contracts, currently held by only 27.3% of respondents.

Such contracts, in addition to ensuring regular supervision, if informed by PDPs, could guide supervision content, ensuring NOS core outcomes are addressed and appropriately targeted within both supervision and CPD activities; current figures suggest fewer respondents were undertaking research /delivering at conferences than identified within other research (67.4% and 74.1% respectively, Golding, 2003).

4.3: Organisation

Despite the absence of supervision contracts, the majority of respondents were undertaking supervision at regular times and subsequently recording a variety of outcomes. Although learning outcomes were least commonly reported (36.4%), this figure exceeded those documented in other studies (21%, DHSSPS, 2003).

Increases have been observed in the numbers of staff holding PDPs and IPRs, accompanied decreases in informal approaches to CPD organisation. In addition, numbers of respondents systematically directing CPD toward meeting personal and organisational needs (45.5%) exceeded those documented in other studies (19% DHSSPS, 2003), whilst informal methods (9% Trust, 18.7% externally financed) were substantially lower (31% DHSSPS, 2003).

In interpreting these results, Trust directors must remain mindful that several respondents failed to list any predominant method of CPD organisation. Furthermore, others adopted a random mix of systematic and ad-hoc methods, particularly for externally financed CPD (54.5%) - this figure exceeding that documented by the DHSSPS: 50%, 2003. Consequently, ambiguity surrounds the ability to ascertain the degree to which these findings may reflect informal methods of organisation, necessitating further clarification.

4.4: Funding of Supervision CPD

Analysis revealed that whilst the majority of both supervision and CPD were Trust financed a substantial proportion of the sample (77.3%), the majority of which did not work externally, were financing CPD through external sources.
Observations that some individuals organised externally funded CPD toward fulfilling Trust objectives and experienced difficulties accessing financial support/time for CPD, suggested that some external funding might reflect self-financed CPD.

Although these findings raise concerns (self-financing of CPD runs contrary to Trust guidelines [2001]) it is important to acknowledge that both the number of respondents organising externally funded CPD toward Trust objectives (18.2%) and the proportion of CPD funded by external sources (28%), remains small. Furthermore, some externally funded events may be free. As such, these findings are limited by failure to explicitly ascertain the proportion of self-financed CPD.

Furthermore, several respondents failed to rate/comment upon barriers to CPD, suggesting that these findings may not be representative of the entire sample. These barriers were also identified within other studies, irrespective of source of funding (Golding, 2003).

Conclusions

The above study provides a wealth of information necessary in preparing for the implementation of BPS re-registration criteria. Whilst improvements are observed in the content and organisation of CPD/supervision, levels and self-financing of CPD remain ambiguous.

Increases in CPD activity will require exploration of the possibility that some staff may be funding their own CPD due to organisational financial/time pressures.

In addition, the awareness of work-based, as opposed to externally-based CPD (which forms part of the Trusts lifelong learning agenda) directed toward a range of outcomes must also continue to be raised (DOH, 1999), redressing outdated notions (still evident within CPD activities of respondents) that CPD equates solely to attending conferences.

REFERENCES


Audit of the Supervision and CPD Activities of Clinical and Counselling Psychologists Working within an NHS Trust


Audit of the Supervision and CPD Activities of Clinical and Counselling Psychologists
Working within an NHS Trust
APPENDIX 1

(SRRP Proposal: Some details changed following submission)

Audit of the Supervision and CPD Activities of Clinical and Counselling Psychologists
Working within an NHS Trust
RESEARCH PROPOSAL FORM

This form should be completed by the candidate and signed by the University supervisor, and then submitted by the deadline in the handbook. An additional section (up to 500 words) may be added to explain the theoretical rationale or reasons for the study in more detail. Remember to give a draft to your supervisor for comments before submitting the final version.

TRAINEE'S NAME:

Project Title:

Audit of Continuing Professional Development and Supervision Activities for Clinical Psychologists within Trust.

Theoretical Rationale:

Consistent with national and regional clinical governance agendas within the NHS there is increasing emphasis on 'life-long learning' and 'professional development'. Subsequently, health professionals across the NHS are encouraged to demonstrate that they are undertaking systematic continuing professional development (CPD).

The British Psychological Society (BPS CPD guidance, 2004) state that 'CPD is vital to personal development and important in demonstrating the public accountability of the profession'. Undertaking CPD activity has been a mandatory requirement for all chartered clinical psychologists since 2000. Whilst most clinical psychologists undertake ongoing CPD within their professional roles, the mandatory requirements of the BPS include the maintenance and submission of a formal record logging CPD activity. From September 2005, continuing registration of all chartered psychologists holding a practising certificate will be dependent upon the submission of such records. These logs will be used to assess both the amount and content of CPD activity, along with the process surrounding the identification of development needs.

The Division of clinical psychology within the BPS states that all clinical psychologists should undertake a minimum of 10 days (70 hours) CPD as standard. A range of CPD activities is identified as relevant including all post-qualification training courses and conferences as well as in-house activities (research, teaching, clinical audit and reading). The exact composition of activities is likely to be dependent on individual development needs.
The DCP outlines a process for undertaking effective CPD. It is suggested that a log is used within supervision to identify training needs. These needs should be prioritised for individual development prior to selecting and implementing development activities. Finally, the development activities undertaken should be recorded and the extent to which learning needs have been met reflected upon.

Supervision, both providing and receiving, are defined as ‘in-house’ CPD activities. The DCP states that clinical psychologists are expected to engage in regular supervision of their own work (research, clinical, managerial, educational) at all stages of their career. The minimum standard of supervision is 60-90 minutes for every 20 sessions worked. Similarly, it is expected that clinical psychologists will provide supervision, particularly to newer members of the profession. Supervision is thus not only part of CPD but also an activity requiring training and development within its own right. Clinical psychologists providing supervision to other members of staff are expected to engage in regular systematic training in models and techniques of supervision (DCP Supervision Guidelines, 2003).

The impending BPS evaluation of practising psychologists’ CPD activity as a requirement for continuing registration makes it necessary to ensure that all clinical psychologists working within NHS Trusts are meeting BPS requirements for CPD activity. The Director of Psychological Therapies within Trust has subsequently identified a need for an analysis of current CPD and supervision activities against the BPS requirements in preparation for the introduction of statutory registration requirements in 2005. Such an analysis will identify areas in which the BPS requirements are not being met, allowing necessary resources to be targeted toward rectifying these discrepancies.

Objective(s):

Specific Objectives:

- To demonstrate the extent to which clinical psychologists working within Trust are undertaking CPD activity.

- To ascertain the nature of current CPD activities being undertaken.

- To explore the extent to which the process of CPD encompasses a systematic identification of development needs and reflection upon the outcome of CPD activities undertaken.
To explore the current level and nature of supervision being received and given by clinical psychologists working within the Trust.

To explore any potential barriers to accessing CPD/supervision perceived by clinical psychologists working within the Trust.

**Overall Objective:**

To undertake an analysis of the level, nature and process of CPD (including supervision) against the BPS requirements for clinical psychologists (working within NHS Trust), in order to maintain standards of professional practise and identify any areas of need to be addressed prior to the implementation of new society requirements in 2005.

**Design:**

- Clinical Audit.

**Setting:**

Psychological Therapies across NHS Trust.

**Participants:**

39 clinical psychologists working within NHS Trust.

**Procedures:**

- Participants will be requested to submit a copy of CPD logs completed and maintained as part of their annual Performance Development Plan. A joint covering letter will be supplied by the researcher and the Trust Director of Psychological Therapies, explaining the purpose and nature of the proposed study.

- Given that the degree to which the CPD logs have been maintained is likely to be variable, participants will also be requested to fill out a brief questionnaire, comprising multiple statements relating to the level, nature and process of CPD/supervision activities undertaken over the past year. Participants will select the statement most appropriate to their experiences/views.

- Copies of CPD logs and questionnaires will be returned to the researcher for analysis.
Main outcome measures (quantitative projects)/broad question areas in interview (qualitative projects):

- The questionnaire will address the level and nature of CPD activity undertaken within the past year, including questions pertaining to the process by which development needs have been identified and the extent to which activities undertaken were evaluated/reflect upon.

- The questionnaire will explore the level and nature of supervision being received and provided by each individual, along with the degree of choice individuals were given when being allocated a supervisor.

- Given that most of the clinical psychologists within the sample work only part-time for the Trust, questions will address the extent to which CPD/supervision activities have been undertaken privately, or within other roles elsewhere.

- An additional section will be included allowing participants to comment on any perceived barriers to Supervision/CPD activities.

Statistical analyses (quantitative projects)/type of qualitative analyses:

Descriptive statistics will be undertaken to analyse the data collected.

Ethical considerations:

It is recognised that participants may feel uncomfortable submitting part of their personal annual appraisal. To address this, participants will be instructed to blank out sections pertaining to evaluations of performance within their current role, questionnaires will also be confidential.

University Supervisor:

Field Supervisor:

Name of Ethics Committee(s) to which project will be submitted:
N/A

Date of next Ethics Committee(s) meeting(s):
N/A

Date of next Research and Development Committee meeting

Audit of the Supervision and CPD Activities of Clinical and Counselling Psychologists Working within an NHS Trust
N/A

Signature of trainee:  Signature of supervisor:
Date:
APPENDIX 2

(Response from Trust Audit Department Following Receipt of Above Proposal)
Dear

Re: PROJECT PROPOSAL - AUDIT

Thank you for your project proposal form for (Audit of CPD/Supervision currently being undertaken by Clinical Psychologists working within ...).

You have been assigned the following number ( ), which must be used on all Trust reporting forms. Your proposal was discussed at the Trust Clinical Audit Committee meeting that was held on (20th January 2005) for approval of general support by the Clinical Effectiveness and Audit Department.

I enclose a copy of the Project Registration Report for your records; On completion of the project please send to the Clinical Audit Department a copy of your report. We keep a copy of all Clinical Audit Reports in the department as we are asked to report on Trust audit activity to National bodies periodically.

Please feel free to contact me on if you require advice on any area of your project.

Yours sincerely

Clinical Audit Effectiveness Facilitator

Audit of the Supervision and CPD Activities of Clinical and Counselling Psychologists
Working within an NHS Trust
Project Reference: AU /

Title: Audit of CPD/Supervision currently being undertaken by Clinical Psychologists working within NHS Trust.

Project Lead:

Objectives: In preparation for the New Society requirements of the BPS due to be implemented in 2005, an audit to ascertain the current levels and process of CPD & Supervision undertaken annually by Clinical Psychologists working with Trust. Perceived barriers to CPD Supervision, along with the extent to which CPD/Supervision is being undertaken within part-time roles elsewhere will also be explored.

Methodology: Clinical Audit. Retrospective descriptive analysis of CPD logs completed across the past year. A Questionnaire will also be distributed addressing issues of the level 1 process of CPD /Supervision, Barriers to CPD Supervision.

Sample Group: 42 Clinical Psychologists working within a variety of settings across NHS Trust.

Participating Orgs: See above

Outcomes:

ETHICS
Approved: □ Advice Sought

TIMESCALES
Start Date: 04/01/2004 End Date: 04/06/2005

CLINICAL AUDIT SUPPORT
Design: □ Data Collection: □ Analysis: □ Report Writing: □

CLINICAL GOVERNANCE MEETING
Approved: □ Date

PROPOSAL FROM:
Date: 22/12/2004

If you have any questions regarding the information in this report please contact:

Audit of the Supervision and CPD Activities of Clinical and Counselling Psychologists Working within an NHS Trust
APPENDIX 3

(Previous Audit Questionnaire, SRRP, Unpublished, 2001)
Psychological Therapies' Supervision and Continuing Professional Development Audit

SECTION A: Personal Details

1. Name

2. Gender
   - Male
   - Female

3. Age (years)

4. Grade
   - Senior
   - Junior
   - Other (if applicable)

5. Number of years qualified

6. Clinical Specialty
   - Clinical Psychologist
   - Counselling Psychologist
   - Psychotherapist
   - Family Therapist
   - Psychotherapist
   - Drama Therapist
   - Music Therapist
   - Art Therapist
   - Counsellor

7. Field of expertise (adult mental health, learning disabilities etc.)

8. Employment
   - Full-time
   - Part-time
   - please specify number of sessions worked

SECTION B: Current Supervision & CPD Arrangements

Please restrict all answers below to your main type of supervision. If you receive more than one type of supervision, please give brief details in Section C

4. Are you currently receiving any supervision of your clinical work? YES/NO
   - YES
   - NO
   - If no please go to question 11

5. What is the average duration and frequency of your main supervision sessions?

   
   Duration | Frequency
   --------------
   30 minutes | Weekly
   1 hour     | Fortnightly
   1.5 hours  | 3-4 weekly
   2 hours    | Less than monthly
   More than 2 hours | 

&/OR Supervision occurs as and when necessary
No regular time (duration or frequency) is set aside

Audit of the Supervision and CPD Activities of Clinical and Counselling Psychologists
Working within an NHS Trust
<table>
<thead>
<tr>
<th>Question</th>
<th>Options</th>
</tr>
</thead>
<tbody>
<tr>
<td>Is your main supervisor</td>
<td></td>
</tr>
<tr>
<td>Internal to your department/immediate place of work.</td>
<td></td>
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<tr>
<td>External to your department/immediate place of work.</td>
<td></td>
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<tr>
<td>Is your main supervisor</td>
<td></td>
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<tr>
<td>A senior or more experienced professional?</td>
<td></td>
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<tr>
<td>Do you receive both peer supervision &amp; supervision from a senior colleague?</td>
<td></td>
</tr>
<tr>
<td>Or does supervision occur only as peer supervision?</td>
<td></td>
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<tr>
<td>Do you generally receive supervision</td>
<td></td>
</tr>
<tr>
<td>Individually?</td>
<td></td>
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<tr>
<td>In a pair?</td>
<td></td>
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<tr>
<td>In a small group?</td>
<td></td>
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<tr>
<td>(please state how many group members there are)</td>
<td></td>
</tr>
<tr>
<td>Is your main supervision</td>
<td></td>
</tr>
<tr>
<td>Trust financed?</td>
<td></td>
</tr>
<tr>
<td>Self-funded?</td>
<td></td>
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<tr>
<td>Other (please specify)</td>
<td></td>
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<tr>
<td>If you are employed part-time by Trust and also work for another employer, who has agreed to fund your supervision?</td>
<td></td>
</tr>
<tr>
<td>Trust</td>
<td></td>
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<tr>
<td>Second employer</td>
<td></td>
</tr>
<tr>
<td>Funding is split</td>
<td></td>
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<tr>
<td>(please specify ratio)</td>
<td></td>
</tr>
<tr>
<td>Self-funded</td>
<td></td>
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<tr>
<td>Has a written supervision contract been drawn up?</td>
<td>YES/NO</td>
</tr>
<tr>
<td>Please indicate which of the following are currently addressed in supervision (please base your response on your last six supervision sessions, and tick as many boxes as are required)</td>
<td></td>
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<tr>
<td>Casework</td>
<td></td>
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<tr>
<td>Administration</td>
<td></td>
</tr>
<tr>
<td>(e.g. review of note-taking &amp; letter writing practice)</td>
<td></td>
</tr>
<tr>
<td>Effective liaison with multidisciplinary teams &amp; other agencies</td>
<td></td>
</tr>
<tr>
<td>Reflective practice</td>
<td></td>
</tr>
<tr>
<td>Review of clinically relevant NHS policy</td>
<td></td>
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<tr>
<td>Discussion of issues regarding race, culture, gender &amp; class</td>
<td></td>
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<tr>
<td>Case presentation skills</td>
<td></td>
</tr>
<tr>
<td>In light of your responses to question 9, would you say that clinical supervision is used primarily for casework discussion?</td>
<td>YES/NO</td>
</tr>
</tbody>
</table>
11 In addition to clinical supervision, do you receive work/case load supervision from your manager?  
| Yes - less than 1 hr per month | | Yes - 1 hr per month | | Yes - more than 1 hr per month | | No | |  

12 Do you supervise:
| Trainees of own profession | YES/NO |
| Traineess of other professions | YES/NO |
| Qualified staff in own profession | YES/NO |
| Qualified staff in other professions | YES/NO |
| Peer supervision | YES/NO |

13 Have you attended a basic training course in supervision?  
If basic training was completed before 1989 have you attended a refresher course within the last three years?  
| YES | NO |

14 Has your work been reviewed/appraised by your Manager in the last twelve months?  
| YES | NO |

15 Have you agreed with your manager:
| A Work Plan? | YES/NO |
| A Professional Development Plan (PDP)? | YES/NO |
| If YES does your PDP include a Continuing Professional Development Plan (CPD)? | YES/NO |

16 If you have agreed a CPD plan with your manager, approximately how many days per annum have been set aside to implement this plan?  
| | | |  

17 Has your CPD Plan been incorporated into the performance review criteria specified in your Work Plan?  
| YES | NO |

18 Please indicate which of the following CPD activities you have engaged in during the last year:
| | |

Audit of the Supervision and CPD Activities of Clinical and Counselling Psychologists  
Working within an NHS Trust
Professional videos (watched with colleagues)
and discussed) [ ]
Paired work with colleague [ ]
Secondment [ ]
Joining a working party (to solve a professional problem) [ ]
Visiting good practice sites [ ]
Research [ ]
(Clinical Audit: development, design, data analysis
and write-up - not participation in work for someone else) [ ]
Other (please specify) [ ]

1) If you have attended any course/conferences in the last year, please give details:

<table>
<thead>
<tr>
<th>Name of event</th>
<th>Number of CPD hours involved</th>
<th>Funding provided by self/Trust</th>
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</table>

2) When discussing the format of your supervision: was this influenced by:
   Your PDP Plan? YES/NO
   Your CPD Plan? YES/NO
   Your Annual Appraisal? YES/NO

SECTION C: Comments

Audit of the Supervision and CPD Activities of Clinical and Counselling Psychologists
Working within an NHS Trust
APPENDIX 4

(Final Questionnaire Developed in Consultation with Trust Directors)

Audit of the Supervision and CPD Activities of Clinical and Counselling Psychologists
Working within an NHS Trust
**BACKGROUND INFORMATION**

1. What is your main theoretical orientation, please tick?

<table>
<thead>
<tr>
<th>ORIENTATION</th>
<th>PLEASE TICK</th>
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</thead>
<tbody>
<tr>
<td>COGNITIVE-BEHAVIOURAL THERAPY</td>
<td></td>
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<tr>
<td>PSYCHODYNAMIC/PSYCHOANALYTIC/CAT THERAPY</td>
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<tr>
<td>SYSTEMIC/FAMILY THERAPY</td>
<td></td>
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<tr>
<td>HUMANISTIC/EXISTENTIAL/PERSON-CENTRED THERAPY</td>
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<tr>
<td>OTHER (PLEASE SPECIFY)</td>
<td></td>
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</tbody>
</table>

**SECTION 1: Supervision**

2. Are you a member of the BPS? Please circle YES/NO

3. If yes, which divisions are you currently a member of? Please circle as appropriate and enter membership renewal date if applicable:

<table>
<thead>
<tr>
<th>TYPE OF MEMBERSHIP</th>
<th>RENEWAL DATE</th>
</tr>
</thead>
<tbody>
<tr>
<td>AFFILIATE</td>
<td>YES/NO</td>
</tr>
<tr>
<td>GRADUATE</td>
<td>YES/NO</td>
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<tr>
<td>CHARTERED</td>
<td>YES/NO</td>
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<tr>
<td>ASSOCIATE FELLOW</td>
<td>YES/NO</td>
</tr>
<tr>
<td>FELLOW</td>
<td>YES/NO</td>
</tr>
</tbody>
</table>

4. Are you on/have you applied for the new foundation membership of the BPS Register of psychologists specialising in psychotherapy? Please circle YES/NO

5. Are you a member of any other professional body, please tick:

<table>
<thead>
<tr>
<th>PROFESSIONAL BODY</th>
<th>FULL/ACCREDITED</th>
<th>TYPE OF MEMBERSHIP</th>
<th>CORRESPONDING</th>
<th>AFFILIATE</th>
</tr>
</thead>
<tbody>
<tr>
<td>UKCP</td>
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<tr>
<td>BABCP</td>
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<tr>
<td>BACP</td>
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<td></td>
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<td></td>
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<tr>
<td>ASSOCIATION OF FAMILY THERAPISTS</td>
<td></td>
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<tr>
<td>OTHER PLEASE SPECIFY</td>
<td></td>
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</tbody>
</table>
6. Please state the number of sessions worked per month within the following locations:

<table>
<thead>
<tr>
<th>LOCATION</th>
<th>NUMBER OF SESSIONS</th>
</tr>
</thead>
<tbody>
<tr>
<td>Trust</td>
<td></td>
</tr>
<tr>
<td>Private Work</td>
<td></td>
</tr>
<tr>
<td>Other NHS Trusts</td>
<td></td>
</tr>
</tbody>
</table>

7. Do you plan supervision at a regular time each month?  
YES/NO

8. Do you have a supervision contract? (please circle)  
YES/NO

9. Please state the number of supervision hours received per month:

<table>
<thead>
<tr>
<th>SUPERVISION PROVIDER</th>
<th>FORMAT OF SUPERVISION RECEIVED (HOURS PER MONTH)</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>FROM SENIOR PROFESSIONAL</td>
<td>SUPERVISED GROUP</td>
</tr>
<tr>
<td>Trust Financed</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Self/Externally-Financed</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

10. Please state the nature of supervision received, number of hours per location:

<table>
<thead>
<tr>
<th>SUPERVISION PROVIDER</th>
<th>NATURE OF SUPERVISION RECEIVED (HOURS PER MONTH)</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>CLINICAL</td>
<td>MANAGERIAL/SERVICE ORGANISATION</td>
</tr>
<tr>
<td>Trust Financed</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Self-/Externally Financed</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

11. Based on your last six supervision sessions (received), which of the following are currently addressed in supervision? Please tick all that apply.

<table>
<thead>
<tr>
<th>ISSUES ADDRESSED IN SUPERVISION</th>
<th>PLEASE TICK</th>
</tr>
</thead>
<tbody>
<tr>
<td>Research</td>
<td></td>
</tr>
<tr>
<td>Therapy</td>
<td></td>
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<tr>
<td>Psychological Assessment</td>
<td></td>
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<tr>
<td>Teaching/Consultancy Work</td>
<td></td>
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<tr>
<td>Service Development Work</td>
<td></td>
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<tr>
<td>Professional Management Issues</td>
<td></td>
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<tr>
<td>Ethics</td>
<td></td>
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<tr>
<td>Diversity</td>
<td></td>
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<tr>
<td>Administration</td>
<td></td>
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<tr>
<td>Reflective Practice</td>
<td></td>
</tr>
<tr>
<td>Review of Clinically Relevant NHS and Professional Policy</td>
<td></td>
</tr>
</tbody>
</table>

Audit of the Supervision and CPD Activities of Clinical and Counselling Psychologists  
Working within an NHS Trust
12. Based on your last six supervision sessions (received), which of the following methods are used in supervision? Please tick all that apply.

<table>
<thead>
<tr>
<th>METHODS USED IN SUPERVISION</th>
<th>PLEASE TICK</th>
</tr>
</thead>
<tbody>
<tr>
<td>CASE DISCUSSION</td>
<td></td>
</tr>
<tr>
<td>REVIEW AUDIO TAPE</td>
<td></td>
</tr>
<tr>
<td>REVIEW VIDEO TAPE</td>
<td></td>
</tr>
<tr>
<td>OBSERVATION AND REVIEW</td>
<td></td>
</tr>
<tr>
<td>ROLE PLAY</td>
<td></td>
</tr>
<tr>
<td>OTHER PLEASE SPECIFY</td>
<td></td>
</tr>
</tbody>
</table>

13. Which of the following, if any, do you record following supervision? Please tick all that apply.

<table>
<thead>
<tr>
<th>INFORMATION RECORDED</th>
<th>PLEASE TICK</th>
</tr>
</thead>
<tbody>
<tr>
<td>LEARNING OUTCOMES</td>
<td></td>
</tr>
<tr>
<td>ACTION PLAN</td>
<td></td>
</tr>
<tr>
<td>REFLECTIVE PRACTICE</td>
<td></td>
</tr>
<tr>
<td>OTHER PLEASE SPECIFY</td>
<td></td>
</tr>
</tbody>
</table>

14. Please state the level of supervision provided by you (hours per month):

<table>
<thead>
<tr>
<th>CLINICAL SUPERVISION PROVIDED BY YOU</th>
</tr>
</thead>
<tbody>
<tr>
<td>TRAINEES OF OWN PROFESSION</td>
</tr>
<tr>
<td>----------------------------------</td>
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<tr>
<td></td>
</tr>
</tbody>
</table>

SECTION 2: CPD

15. Please indicate (tick) in the boxes below, your predominant method of CPD organisation.

<table>
<thead>
<tr>
<th>CPD PROVIDER</th>
<th>SYSTEMATIC-PLANNED (TOWARD MEETING OBJECTIVES IDENTIFIED IN LAST APPRAISAL)</th>
<th>SYSTEMATIC-PLANNED (TOWARD MEETING PERSONAL CAREER PROGRESSION NEEDS)</th>
<th>AD-HOC (CPD OPPORTUNITIES NOT PLANNED/INTEGRATED WITH PERSONAL NEEDS/TEAM OBJECTIVES)</th>
</tr>
</thead>
<tbody>
<tr>
<td>TRUST</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>SELF/EXTERNALLY FINANCED</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

16. Have you had an Independent Performance Review during the past year? YES/NO

Audit of the Supervision and CPD Activities of Clinical and Counselling Psychologists Working within an NHS Trust
17. Do you have a current Personal Development Plan? Please circle YES/NO

18. Please outline your current CPD objectives in the spaces below.

<table>
<thead>
<tr>
<th>DEVELOPMENT NEEDS IDENTIFIED</th>
<th>To Meet the Requirements of Your Current Role</th>
<th>To Meet Personal Objectives</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

19. Please indicate whether you have undertaken any CPD directed toward the following outcomes in past year. Please tick all that apply.

<table>
<thead>
<tr>
<th>Goal of CPD</th>
<th>Trust Financed</th>
<th>Self/Externally-Financed</th>
</tr>
</thead>
<tbody>
<tr>
<td>Improving Understanding of Ethical Issues*</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Improving Clinical Practice*</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Research &amp; Evaluation*</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Improving Communication* (of Psychological Knowledge and Policy Requirements)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Training* (Focused toward developing knowledge of practices, skills etc)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>PERSONAL DEVELOPMENT</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Management* (Geared toward improving provision of services/resources)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Improving Supervision Provision Skills</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

* Based on BPS Core Outcomes for Practising Psychologists (Society Requirements for Continuing Professional Development)
20. Please indicate CPD activities undertaken in the last year (approximate hours spent on each):

<table>
<thead>
<tr>
<th>Activity</th>
<th>Trust Financed</th>
<th>Self/Externally-Financed</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>EXTERNAL DELIVERED</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Presented at conferences, seminars, workshops, courses.</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>EXTERNAL RECEIVED</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Attended conferences, seminars, workshops, courses</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>IN-HOUSE</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Research and development</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>READING/STUDY/LITERATURE REVIEW</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Observation/Shadowing/co-working</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>PERSONAL THERAPY/ MENTOR</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>OTHER, PLEASE SPECIFY</strong></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

21. Please indicate the number of hours external CPD received from selected organisations:

<table>
<thead>
<tr>
<th>Organisation</th>
<th>Trust Financed</th>
<th>Self/Externally-Financed</th>
</tr>
</thead>
<tbody>
<tr>
<td>BPS Division of Clinical Psychology</td>
<td></td>
<td></td>
</tr>
<tr>
<td>BPS SpIG for your speciality</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other Psychological Therapy Organisation e.g. UKCP, BABCP</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Multidisciplinary therapy training</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Multidisciplinary care group training</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Multidisciplinary management training</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>OTHER PLEASE SPECIFY</strong></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Audit of the Supervision and CPD Activities of Clinical and Counselling Psychologists
Working within an NHS Trust
22. Please **rank, in order of priority, the factors which prevent you obtaining CPD within Trust:**

<table>
<thead>
<tr>
<th>POTENTIAL BARRIER</th>
<th>ORDER OF IMPORTANCE 1-7 (1= MOST IMPORTANT BARRIER TO CPD, 7= LEAST IMPORTANT)</th>
</tr>
</thead>
<tbody>
<tr>
<td>LACK OF FINANCIAL SUPPORT</td>
<td></td>
</tr>
<tr>
<td>LACK OF ORGANISATIONAL SUPPORT</td>
<td></td>
</tr>
<tr>
<td>LACK OF TIME TO INTEGRATE CPD BASED LEARNING INTO PRACTICE</td>
<td></td>
</tr>
<tr>
<td>LACK OF SUPPORT FROM MANAGER IN TAKING TIME OFF FOR CPD</td>
<td></td>
</tr>
<tr>
<td>PERSONAL COMMITMENTS (E.G. CHILDCARE)</td>
<td></td>
</tr>
<tr>
<td>PRESSURE OF CLINICAL WORK</td>
<td></td>
</tr>
<tr>
<td>LACK OF INFORMATION REGARDING CPD OPPORTUNITIES.</td>
<td></td>
</tr>
</tbody>
</table>

23. In the space below, please list any other factors that prevent you from accessing CPD within Trust.

THANK YOU FOR YOUR PARTICIPATION
APPENDIX 5

(Factors Hindering CPD Identified by Golding, 2003)
Factors Hindering CPD Identified by Golding 2003.

- Lack of Time
- Lack of Financial Support From Employer
- Pressure of Clinical Work
- Lack of Information about Resources
- Quality of Activities Available
APPENDIX 6

(Cover Letter Included with Mail-Out)
Please Return To

FROM:  
PSYCHOLOGICAL THERAPIES DIRECTOR  

CLINICAL PSYCHOLOGIST IN TRAINING  

TO:  
CLINICAL PSYCHOLOGISTS  
COUNSELLING PSYCHOLOGISTS  

RE: SUPERVISION AND CPD AUDIT

As you will know the BPS Continuing Professional Development requirements have become more rigorous (see attached information sheets). Please find attached a questionnaire, which I would be grateful if you would complete and return to me as soon as possible.

I need this information to establish whether Psychologists are meeting the BPS criteria for Supervision and CPD necessary for the renewal of their practicing certificate. who will be analysing the data and writing the report, also needs the information to fulfil the research requirements of her first year on the training course.

and I have tried to keep the questions as brief as possible, given the complexity of the BPS recommendations concerning the level, process and organisation CPD. I am also interested in any barriers preventing CPD access within the Trust and would welcome any comments or extra information you may wish to provide concerning this.

Given the importance of the new society requirements for ensuring the continuing practice of Psychologists, a 100% return rate is vital in ascertaining areas of need within the Trust.

The questionnaires should be returned to at the above address, preferably within two weeks. Although the questionnaire asks for your name, grade and team base. On receipt of the completed questionnaires, will ensure that only the anonymised data is transferred to for data entry and analysis by detaching this information from the completed questionnaires. Subsequently the reporting data will reflect group responses and no reference to the names of individuals or comments about individuals will be made.

will keep a log of staff members who have returned their questionnaires enabling her to chase non-respondents. This is necessary to ensure a high
response rate and an accurate reflection of current CPD and Supervision activity within the Trust necessary for the targeting of future resources.

If anyone has worries or concerns about CPD or Supervision which they need to discuss with me personally, please contact and arrange a time to meet.
APPENDIX 7

(BPS Guidance Included with Mail-Out)
October 2004

Dear Colleague,

Continuing Professional Development (CPD) – New Society Requirements

CPD is vital to personal development and important in demonstrating the public accountability of the profession. This was evidenced when the membership voted to make CPD mandatory in 2000. Most psychologists undertake ongoing CPD as a normal part of professional life, but mandatory CPD requires them to show this by maintaining and submitting a formal record.

From September 2005 onwards, as a Chartered Psychologist holding a Practising Certificate, you will be asked to submit an annual record of CPD to the Society to link with the renewal of your Practising Certificate. The aim of this letter is to give you the opportunity to plan and record your CPD for at least a year prior to the first CPD submission. The new CPD requirements are summarised in the enclosed leaflets. The Society website (www.bps.org.uk/cpd) also contains CPD information, together with access to the Online Planning and Recording System. Plans are being made to hold a series of introductory workshops at Branch venues, please see the website or contact your local Branch for details. There will also be a telephone and e-mail CPD helpline available to answer members’ queries.

The CPD Online Planning and Recording System has been developed in response to feedback received from members taking part in the CPD pilot study. It provides a paperless and simple way for you to compile and maintain up to five years of your CPD record in a confidential area of the Society website.

A MS Word version of the planning and recording documentation will be available via e-mail or disk to those who do not have Internet access, but hand written CPD submissions cannot be accepted. Individual arrangements will be made for those with visual impairment or other special requirements.

You will be aware that critical decisions are still to be made regarding the regulation of psychologists by the Health Professions Council (HPC). The HPC is currently undertaking a CPD consultation which we are following closely, will be responding to and are hoping to influence. Whilst the full implications of these developments are not yet clear, we are fully committed to the Society CPD process which has been extensively trialled and consulted on, and which both reflects and supports best practice in applied psychology.

We hope that you will find the online CPD system a useful tool for managing your professional development. We would also like to thank all the members who have provided comments and feedback at various stages in this project, and look forward to receiving feedback to inform the evolution of the CPD scheme.

Yours sincerely,

Emeritus Professor Ken Brown
President

Amanda Harris
Chair – Standing Committee for CPD
URN:2432874

Audit of the Supervision and CPD Activities of Clinical and Counselling Psychologists
Working within an NHS Trust
Do the CPD requirements apply to you?
Mandatory CPD applies to all chartered psychologists who hold a Practising Certificate and requires individuals to be able to show that they are engaging in the CPD process. The starting point for CPD is when a psychologist gains chartered status and receives their first Practising Certificate. As one of the aims of CPD is to provide an indicator of maintenance of professional competence, the Society's CPD requirements apply to all chartered psychologists holding a Practising Certificate irrespective of the number of hours worked or degree of experience.

What is the purpose of mandatory CPD?
As well as being vital to personal development, CPD is important in demonstrating the public accountability of the profession. CPD is taken as an indicator of maintenance of professional competence, hence the requirement for individuals to maintain and submit formal records. The system is intended to be sufficiently flexible to take account of the requirements and procedures of psychologists' employing organisations and other professional associations.

What are the CPD requirements?
The requirements outlined below are intended to ensure that there is a focus on outcomes (i.e. the development of competencies) rather than, for example, a record of time spent on formal training courses. Individuals will need to demonstrate their continuing professional competence within their own specific scope of practice through providing evidence of CPD.

Chartered Psychologists holding a Practising Certificate are required to maintain and submit a record of CPD to the Society to demonstrate fulfilment of core outcomes based on the Key Roles of the National Occupational Standards (NOS) for Applied Psychologists (Generic).

1. Ethics - Develop, implement and maintain personal and professional standards and ethical practice.
2. Practice - Apply psychological and related methods, concepts, models, theories and knowledge derived from reproducible research findings.
3. Research and Evaluation - Research and develop new and existing psychological methods, concepts, models, theories and instruments in psychology.
4. Communication - Communicate psychological knowledge, principles, methods, needs and policy requirements.
5. Training - Develop and train the application of psychological skills, knowledge, practices and procedures.
6. Management - Manage the provision of psychological systems, services and resources.

The first four Key Roles are common to all chartered psychologists, and individuals must be able to relate their CPD to cover at least some aspect of each of these. Training and Management roles will apply where relevant to an individual's role as a practicing psychologist. Further information about the NOS Key roles and the units which comprise them is available in a separate leaflet, National Occupational Standards in Applied Psychology (Generic) - Quick Reference Summary.

In line with the Society's Equal Opportunities Statement and Policy all psychologists will need to ensure that they maintain an up-to-date knowledge of equal opportunities issues and how these can impact on their day-to-day work as a member of the profession.

What is the Society's Recording System for CPD?
CPD records should be submitted in the form of a Summary Log which includes details of the CPD process undertaken in the previous year:
- The professional development needs identified for that year;
- The development activities undertaken;
- An overview of the Individual psychologist's review and reflection on the learning outcomes and how this relates...
Any further/future development needs identified as a result of the review and reflection.

The format for planning and recording CPD is common for all chartered psychologists to use and consists of three documents:
1. Plan - lists identified development needs and any activities planned to meet these.
2. Record of Activity - allows recording of each separate CPD activity undertaken (this includes any additional unplanned activities as well as those planned for). Includes space for a description of the activity, reflective evaluation and any future development needs identified.
3. Summary Log - brings together the activities undertaken against each development need and shows the relationship to the relevant NOS Key Role.

The CPD Summary Log is the only document that you will be required to submit in the first instance. The first two documents are primarily provided to aid the planning process and help you manage your CPD in an organised way, but may be helpful for reference later if your record is selected as part of the sample for qualitative monitoring.

An online recording facility is available in the Members’ area of the Society website (www.bps.org.uk/cpd). This provides a confidential and straightforward way for you to compile and maintain your CPD records and allows you to keep up to five years of records for reference.

What if I do not have Internet access?
You will be able to request a MS Word version of the planning and recording documentation. Please note that handwritten records cannot be accepted; all members are asked to complete a word-processed format to ensure legibility.

Special arrangements will be made for those with visual impairment; please contact us if you have special requirements.

How often will I need to submit information?
You will be required to submit your CPD Summary Log on an annual basis, prior to renewal of your Practising Certificate. You will be asked to submit your CPD record three months before the month in which your Practising Certificate is renewed e.g. if your Practising Certificate renewal falls in January, your CPD year will run from 1 October to 30 September, and you will be asked to submit your CPD in October 2005. The table below shows the submission times for each Practising Certificate renewal time:

<table>
<thead>
<tr>
<th>Practising Certificate renewal time</th>
<th>Submission time for CPD record</th>
</tr>
</thead>
<tbody>
<tr>
<td>January 2006</td>
<td>October 2005</td>
</tr>
<tr>
<td>April 2006</td>
<td>January 2006</td>
</tr>
<tr>
<td>July 2006</td>
<td>April 2006</td>
</tr>
<tr>
<td>September 2006</td>
<td>July 2006</td>
</tr>
</tbody>
</table>

What kinds of activities are relevant to CPD?
Psychologists should undertake a range of different CPD activities, the exact composition of which will depend upon individual development needs.

Examples of activities which might be used for CPD
CPD can encompass a broad range of activities, both formal and informal. It is important to remember that most psychologists are already engaging in many of these activities as a normal part of their professional life. The following list sets out some examples; this list is not exhaustive and there may be other development activities that individual psychologists might wish to use:
- Post-qualification training courses;
- Received or conferred professional supervision in an area of psychology;
- Presentation or attendance at conferences;
- ...
Preparation for new/updated material for teaching, training or publication;
Attendance at courses according to the individual’s needs;
Peer group discussion;
Professional committee work;
Reading;
Learning from participation in multidisciplinary meetings and events;
Personal psychological counseling for professional purposes;
Systematic reflection on practice.

The balance of activities undertaken is likely to vary at different stages in a psychologist’s career. The individual psychologist will choose a range of activities which they consider will best meet their own development needs and particular circumstances.

What will be my commitment in terms of hours?
The assessment of CPD will be based on the quality and outcomes of CPD activity, rather than merely being a measure of the amount of time spent. As a guide, the Society recommends a minimum of 40 hours of CPD activity per year as being necessary to maintain professional competence, and most psychologists will show considerably more than this.

How will my CPD activity be monitored?
The receipt of an appropriately completed CPD record will trigger the issue of your Practising Certificate for the year ahead. In order to enable the Society to undertake a qualitative evaluation of the CPD process, a random sample (proportionate by Division) will be selected for detailed scrutiny by Divisional CPD assessors. The CPD plans and records of those returning to practice after a break will also be scrutinized by CPD assessors during the first year of their return. This is to ensure the process is operating effectively, and to gain a better understanding of members’ support needs. Members will be asked to nominate a Division to which their work most closely relates for monitoring purposes.

What is my Division’s involvement with CPD requirements?
The requirements set out above are common for members of all Divisions. In addition, some Divisions provide additional CPD guidance for their members within this general framework. CPD assessors from the Divisions will undertake the qualitative assessments and a cross-society panel will moderate the qualitative monitoring process to ensure consistency.

What if I am a full member of more than one Division?
Those holding membership of several Divisions will be asked to nominate one Division (that to which the majority of their work most closely relates) for monitoring purposes.

What if I hold a Practising Certificate but am not a member of a Division?
You will also be asked to nominate an appropriate Division for monitoring purposes.

What if I am on maternity leave or long-term sick leave?
If you are unable to fulfill the CPD requirements for a particular year for reasons such as maternity leave or long-term sick leave, you will need to inform the Society.

What if I need a Practising Certificate after a period of exemption?
Exemptions from holding a Practising Certificate are generally granted on the basis that individuals are not offering or agreeing to provide psychological services or if they are engaged in the acquisition and dissemination of psychological knowledge for purely academic purposes. If you currently have exemption from holding a Practising Certificate and now wish to apply for one, you will be able to obtain a Practising Certificate on submission of an appropriate plan of CPD and the requisite fee. You will be required to submit your CPD record for qualitative assessment at the end of six months and one year.

What if I am a newly qualified psychologist?
You will automatically receive your first Practising Certificate once you have gained chartered status and join the Register of Chartered Psychologists, provided there is no break between qualification and starting to practice. It will then become necessary to submit your CPD Summary Log for annual renewal of your Practising Certificate.
APPENDIX 8

(Raw Frequency Data: Sample Demographics)
Sample Demographics

Table 4: Frequency of Respondents within Different Age Ranges:

<table>
<thead>
<tr>
<th>Age Range</th>
<th>No. Respondents</th>
</tr>
</thead>
<tbody>
<tr>
<td>21-25</td>
<td>1</td>
</tr>
<tr>
<td>26-30</td>
<td>2</td>
</tr>
<tr>
<td>31-35</td>
<td>0</td>
</tr>
<tr>
<td>36-40</td>
<td>4</td>
</tr>
<tr>
<td>41-45</td>
<td>4</td>
</tr>
<tr>
<td>46-50</td>
<td>2</td>
</tr>
<tr>
<td>51-55</td>
<td>6</td>
</tr>
<tr>
<td>56-60</td>
<td>3</td>
</tr>
<tr>
<td>TOTAL</td>
<td>22</td>
</tr>
</tbody>
</table>

Locations of Sessions Worked

Figure 8: SPPS Output Sessions: Frequencies, Number of Sessions Worked Various Locations.
Figure 9: Percentages & Frequencies of Respondents Working in Various Services

- 10, 44%
- 5, 23%
- 3, 14%
- 2, 9%
- 1, 5%
- 1, 5%
- 1, 5%

Legend:
- □ Adult CMHT
- ■ Adult Primary Care
- □ Adult Specialist Psychology (Neuro & Health)
- □ Adult Drug & Alcohol Services
- ■ Adult Learning Disabilities
- □ Elderly CMHT

Audit of the Supervision and CPD Activities of Clinical and Counselling Psychologists
Working within an NHS Trust
APPENDIX 9

(Level of Supervision Frequency Data)
Frequencies, Level of Supervision

Table 5: Total Number of Sessions Worked, Supervision Hours Received and Target Number of Supervision Hours (If 4 in group).

Counselling psychologists do not require a target figure to be calculated.

<table>
<thead>
<tr>
<th>Participant Number</th>
<th>Total Number of Sessions Worked (per month)</th>
<th>Total Number of Supervision hrs (per month if 4 in group)</th>
<th>Target No. Hours Received to Meet 60 minute Criteria</th>
<th>Target No. Hours Received to Meet 90 minute Criteria</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>10</td>
<td>2</td>
<td>0.5</td>
<td>0.75</td>
</tr>
<tr>
<td>2*</td>
<td>41</td>
<td>4.5</td>
<td></td>
<td></td>
</tr>
<tr>
<td>3</td>
<td>10</td>
<td>4</td>
<td>0.5</td>
<td>0.75</td>
</tr>
<tr>
<td>4</td>
<td>8</td>
<td>7</td>
<td>0.4</td>
<td>0.6</td>
</tr>
<tr>
<td>5*</td>
<td>40</td>
<td>2.5</td>
<td></td>
<td></td>
</tr>
<tr>
<td>6</td>
<td>6.5</td>
<td>3.81</td>
<td>0.325</td>
<td>0.4875</td>
</tr>
<tr>
<td>7</td>
<td>8</td>
<td>6.5</td>
<td>0.4</td>
<td>0.6</td>
</tr>
<tr>
<td>8</td>
<td>10</td>
<td>7</td>
<td>0.5</td>
<td>0.75</td>
</tr>
<tr>
<td>9</td>
<td>20</td>
<td>3.29</td>
<td>1</td>
<td>1.5</td>
</tr>
<tr>
<td>10*</td>
<td>5</td>
<td>4.5</td>
<td></td>
<td></td>
</tr>
<tr>
<td>11</td>
<td>20</td>
<td>1</td>
<td>1</td>
<td>1.5</td>
</tr>
<tr>
<td>12</td>
<td>32</td>
<td>5</td>
<td>1.6</td>
<td>2.4</td>
</tr>
<tr>
<td>13*</td>
<td>4</td>
<td>2.75</td>
<td></td>
<td></td>
</tr>
<tr>
<td>14</td>
<td>10</td>
<td>4</td>
<td>0.5</td>
<td>0.75</td>
</tr>
<tr>
<td>15</td>
<td>40</td>
<td>2</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>16*</td>
<td>9</td>
<td>2</td>
<td></td>
<td></td>
</tr>
<tr>
<td>17*</td>
<td>20</td>
<td>2</td>
<td></td>
<td></td>
</tr>
<tr>
<td>18</td>
<td>4.5</td>
<td>2.75</td>
<td>0.225</td>
<td>0.3375</td>
</tr>
<tr>
<td>19</td>
<td>5.17</td>
<td>5.5</td>
<td>0.2585</td>
<td>0.38775</td>
</tr>
<tr>
<td>20</td>
<td>32</td>
<td>99</td>
<td>1.6</td>
<td>2.4</td>
</tr>
<tr>
<td>21</td>
<td>8</td>
<td>3</td>
<td>0.4</td>
<td>0.6</td>
</tr>
<tr>
<td>22</td>
<td>9</td>
<td>0</td>
<td>0.45</td>
<td>0.675</td>
</tr>
</tbody>
</table>

* Counselling psychologists do not require a target figure to be calculated.
Table 6: Total Sessions Worked, Number of Supervision Hours Received and Target Number of Supervision Hours Received (If 8 in Group).

<table>
<thead>
<tr>
<th>Participant Number</th>
<th>Total Number of Sessions Worked (per month)</th>
<th>Total Number of Supervision hrs (per month if 8 in group)</th>
<th>Target No. Hours Received to Meet 60 minute Criteria</th>
<th>Target No. Hours Received to Meet 90 minute Criteria</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>10</td>
<td>2</td>
<td>0.5</td>
<td>0.75</td>
</tr>
<tr>
<td>2*</td>
<td>41</td>
<td>4.25</td>
<td></td>
<td></td>
</tr>
<tr>
<td>3</td>
<td>10</td>
<td>4</td>
<td>0.5</td>
<td>0.75</td>
</tr>
<tr>
<td>4</td>
<td>8</td>
<td>7</td>
<td>0.4</td>
<td>0.6</td>
</tr>
<tr>
<td>5*</td>
<td>40</td>
<td>2.5</td>
<td></td>
<td></td>
</tr>
<tr>
<td>6</td>
<td>6.5</td>
<td>3.53</td>
<td>0.325</td>
<td>0.4875</td>
</tr>
<tr>
<td>7</td>
<td>8</td>
<td>6.25</td>
<td>0.4</td>
<td>0.6</td>
</tr>
<tr>
<td>8</td>
<td>10</td>
<td>7</td>
<td>0.5</td>
<td>0.75</td>
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<td>9</td>
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<td>1.5</td>
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<td>10*</td>
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<td>4.25</td>
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<td>1</td>
<td>1.5</td>
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<td>32</td>
<td>5</td>
<td>1.6</td>
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<td>13*</td>
<td>4</td>
<td>2.38</td>
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<td></td>
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<td>10</td>
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<td>0.5</td>
<td>0.75</td>
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<td>15</td>
<td>40</td>
<td>2</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>16*</td>
<td>9</td>
<td>2</td>
<td></td>
<td></td>
</tr>
<tr>
<td>17*</td>
<td>20</td>
<td>3.75</td>
<td></td>
<td></td>
</tr>
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<td>4.5</td>
<td>2.75</td>
<td>0.225</td>
<td>0.3375</td>
</tr>
<tr>
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<td>5.17</td>
<td>5.25</td>
<td>0.2585</td>
<td>0.38775</td>
</tr>
<tr>
<td>20</td>
<td>32</td>
<td>99</td>
<td>1.6</td>
<td>2.4</td>
</tr>
<tr>
<td>21</td>
<td>8</td>
<td>3</td>
<td>0.4</td>
<td>0.6</td>
</tr>
<tr>
<td>22</td>
<td>9</td>
<td>0</td>
<td>0.45</td>
<td>0.675</td>
</tr>
</tbody>
</table>

* Counselling psychologists do not require a target figure to be calculated.
Calculating Target Number of Supervision Necessary to Meet DCP Criteria:

For each respondent, the total level of supervision (hours) received (group, individual and peer), was contrasted with a target figure necessary to fulfil BPS criteria, calculated using the following formula:

\[
\frac{\text{Sessions worked}}{X1 \text{ or } 1.5} = \text{Target}
\]

DCP guidelines (1999) state that supervision undertaken within supervised groups must be divided by the number of supervisee’s present within the group.

As supervision groups vary in size, the total time spent within each group was divided by 4 (figure developed after consultation with Trust Directors, to represent a minimum number of supervisee’s within most groups. This figure was then increased to 8 to explore whether variations in group size impacted on whether BPS criteria were met.
APPENDIX 10

(Level of CPD Undertaken: Boxplots and Frequency Data)
Level of CPD

**Figure 10:** Boxplot presenting spread of scores, total number of hours CPD undertaken.

**Figure 11:** Number of Hours CPD Undertaken by Clinical and Counselling Psychologists (n=22):

Audit of the Supervision and CPD Activities of Clinical and Counselling Psychologists Working within an NHS Trust
Table 7: Mean Number of CPD hours Undertaken:

<table>
<thead>
<tr>
<th></th>
<th>N</th>
<th>Minimum</th>
<th>Maximum</th>
<th>Mean</th>
<th>Std. Deviation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Totalhrs</td>
<td>16</td>
<td>23.00</td>
<td>176.00</td>
<td>83.25</td>
<td>39.63584</td>
</tr>
<tr>
<td>Valid N (listwise)</td>
<td>16</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Figure 12: Percentage of respondents undertaking various combinations of supervision.

Audit of the Supervision and CPD Activities of Clinical and Counselling Psychologists
Working within an NHS Trust
APPENDIX 11

(SPSS Frequency Outputs: Format of Supervision)

Audit of the Supervision and CPD Activities of Clinical and Counselling Psychologists Working within an NHS Trust
Figure 13: Frequencies, Format of Supervision Received.

Audit of the Supervision and CPD Activities of Clinical and Counselling Psychologists
Working within an NHS Trust
APPENDIX 12

(Means & Boxplots: CPD Activities)
Figure 14: Boxplot Highlighting Spread of Scores in The Number of Hours Spent on Various CPD Activities.

Audit of the Supervision and CPD Activities of Clinical and Counselling Psychologists Working within an NHS Trust
APPENDIX 13

(Mean Ratings: Barriers to CPD)
Figure 15: Barriers to CPD: Mean Ratings Achieved (1=most important, 7=least important).

Audit of the Supervision and CPD Activities of Clinical and Counselling Psychologists
Working within an NHS Trust
APPENDIX 14

(Qualitative Analysis of Barriers to CPD)
Qualitative Analysis: Barriers to CPD

Comments made in response to question 23 concerning barriers to CPD, were separated by the researcher into thematic units (as advised in Cooligan, 1994). Subsequently, these units were coded according to their primary content generating categories pertaining to:

1. No difficulties accessing CPD;
2. Funding
3. Lack of Relevance of CPD Activities
4. Time Pressures

A second researcher was presented with the thematic units and asked to re-code the data, adding an additional fifth category "other" to allow the rater scope to disagree with all categorisation codes. Table 8 highlights that 91% agreement in categorisation was obtained yielding a Kappa coefficient of 0.88 calculated using the following formula:

\[ K = \frac{\sum a - \sum ef}{N - \sum ef} \]

Where:
- \( \sum a \) = Number of agreements
- \( \sum ef \) = Sum of expected frequencies, calculated by multiplying row and column totals together and dividing by \( N \) (see figures in brackets, Table 8).
<table>
<thead>
<tr>
<th>Respondent No</th>
<th>Comments Made (split into thematic units)</th>
<th>Categorisation</th>
</tr>
</thead>
<tbody>
<tr>
<td>5</td>
<td>I have found no difficulty in fulfilling CPD and supervision requirements. However, lack of funding for external training/conferences/seminars etc. limits the range of CPD undertaken</td>
<td>No difficulties</td>
</tr>
<tr>
<td>9</td>
<td>Most of the training available is not relevant to psychology as it is aimed at other employees within the Trust.</td>
<td>Lack of Relevance</td>
</tr>
<tr>
<td>11</td>
<td>Part time work limits my ability to access CPD- as CPD eats into my clinical work time/difficult to take back time in lieu for things I attend. Also, have previously paid for childcare to enable me to attend workshop which I should have claimed back</td>
<td>Time pressures</td>
</tr>
<tr>
<td>14</td>
<td>Most of the training available is not relevant to psychology as it is aimed at other employees within the Trust.</td>
<td>Lack of Relevance</td>
</tr>
<tr>
<td>15</td>
<td>Not being given time to access CPD outside Trust.</td>
<td>Time Pressures</td>
</tr>
<tr>
<td>19</td>
<td>Pressure of other work (non-clinical). Lack of appropriate training opportunities</td>
<td>Time Pressures</td>
</tr>
<tr>
<td>21</td>
<td>Would like to add that I receive general good support in accessing CPD.</td>
<td>Good Support</td>
</tr>
<tr>
<td>22</td>
<td>Nothing on offer for my level/type of work.</td>
<td>Lack of Relevance</td>
</tr>
</tbody>
</table>
Table 8: Contingency Analysis of Ratings Given By Both Researchers for Qualitative Data Pertaining to CPD Barriers.

<table>
<thead>
<tr>
<th>Categorisation Variables</th>
<th>Number of Agreements Between Raters</th>
<th>Column Total</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Rater 1</td>
<td>1</td>
</tr>
<tr>
<td>1 (No Difficulties)</td>
<td>1 (0.19)</td>
<td></td>
</tr>
<tr>
<td>2 (Funding)</td>
<td>2 (0.36)</td>
<td></td>
</tr>
<tr>
<td>3 (Relevance)</td>
<td>4 (1.45)</td>
<td></td>
</tr>
<tr>
<td>4 (Time)</td>
<td></td>
<td>3 (0.82)</td>
</tr>
<tr>
<td>5 (Other)</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>Row Total</td>
<td>2</td>
<td>2</td>
</tr>
</tbody>
</table>
APPENDIX 15

(Feedback to and From Trust Directors)

Audit of the Supervision and CPD Activities of Clinical and Counselling Psychologists
Working within an NHS Trust
A copy of this report has been given to the Director of Psychological Therapies within the Trust. A full report, inclusive of areas findings not reported within this SRRP (due to word constraints), will also be provided and the findings disseminated to respondents sampled, as deemed appropriate by Trust Directors, as part of future efforts to address issues raised within the discussion.

Response from Trust Director:

Dear

Good to hear from you!

I actually had your project paper out only last Friday to consider how we can use it in the light of our new supervision policy to re-audit and see if we are making progress. What a strange co-incidence.

I can certainly confirm that you developed the idea for your project and carried it out whilst you were my trainee in the to help us determine where we needed to focus attention to ensure we were complaint with the new BPS guidelines. You presented the work to our Clinical Governance meeting and led a group discussion about how we could address some of the more challenging findings. Since then we have emailed and corresponded a couple of times when I have needed further advice about the data.

good luck with finishing your course and applications for jobs

with best wishes
APPENDIX 16

(SRRP Ethical Approval Disclaimer)
The nature of the proposed project is such that I am satisfied that it will not require scrutiny by the trust's ethical committee.

Name of Field/Placement Supervisor

Signature of Field/Placement Supervisor:

Name of Trainee: N C Chaloner

Title of SRRP: Audit of the Supervision and CPD Activities of Clinical and Counselling Psychologists Working within an NHS Trust

Date: 21/3/10
QUALITATIVE RESEARCH PROJECT

"""Newspaper constructions of risk following protests about the publication of cartoons depicting the Prophet Mohamed: A discourse analysis."

Year 2: May 2006
SUMMARY OF GROUP QUALITATIVE RESEARCH PROJECT

Objectives: The current study focussed on the media response to the “cartoon” incident of September 2005 during which a Danish newspaper published “cartoons” depicting the Islamic prophet Muhammad. Specifically, the study aimed to explore media representations of Muslims and Islam in response to this incident, focussing on the depictions of risk and threat conveyed within British newspapers.

Method: In exploring these aims, a qualitative research methodology was employed. Specifically, newspaper extracts (including text and images) relating to the depiction of threat and risk were selected from papers of varying political affiliations, before being subjected to a detailed discourse analysis, exploring the text’s discursive organisation and possible functional orientations. Here, a critical discursive psychology approach was undertaken, integrating elements of previously distinct discursive and Foucauldian discourse analytic traditions, within a social constructionist framework.

Results: Extracts of texts and images were discussed in relation to the following two predominant themes, ‘the separation of the majority Muslim community from the ‘extremists’” and ‘the protestors as wild men bringing Armageddon on the West’.

Conclusions: The study concluded by considering the way in which the British media generally portrayed Muslims in a negative light, reinforcing notions of risk/danger through use of simplistic text and imagery supporting these positions. In doing so the current findings were contrasted alongside wider literature from the field with regard to the study’s potential limitations.
Contemplating the Future with Chronic Fatigue Syndrome: A Grounded Theory Exploration of the Experience of Self and Contemplation of the Future among Individuals with Chronic Fatigue Syndrome

Year 3: July 2007
ACKNOWLEDGEMENTS

I would like to thank all of those people who were willing to give me their time in talking about their experiences of living with Chronic Fatigue Syndrome. I appreciate that this was at times an emotional and challenging subject to discuss and I am extremely grateful for each and every frank insight and perspective shared with me across the interviews.

I would also like to thank both my Research tutor and Field supervisor (with whom my experiences provided the inspiration for the current subject area) for their invaluable advice and support throughout the planning, implementation and write up of this study.

Finally I would like to express my gratitude to the team secretary within the base where the study took place for her support in being my contact point across the interviews and in relaying any questionnaires/personal details to me during the recruiting and interview stages of the project.
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N C Chaloner Research Dossier: Major Research Project

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Contemplating the Future in CFS: A Grounded Theory Exploration of the Experience of Self and Contemplation of the Future Across Individuals with Chronic Fatigue Syndrome
ABSTRACT

Objectives: To explore the ways in which individuals with Chronic Fatigue Syndrome (CFS) think about themselves and their futures.

Participants and Setting: Seven individuals (five women, two men) were recruited from a psycho-educational group within a specialist psychological therapies service in the south of England.

Methodology: A qualitative investigation was undertaken using a Grounded Theory methodology to interview, analyse and interpret participants' experiences with regards to the above objectives.

Results: The experience of developing CFS was observed as presenting a major challenge to participants' sense of who they are, alongside their willingness to contemplate the future. More specifically, continual experiences of uncertainty (symptomatic, aetiological and prognostic) alongside changed relationships, influenced attempts to make sense of the illness experience, eliciting dilemmas of illness validity and agency. The process of negotiating self-illness changes is subsequently rendered a complex and fluid process, marked by fluctuating degrees of integration between self and illness, posing dilemmas for individuals' willingness to integrate and accommodate illness within expectations for the future.

Conclusions: The experience of developing and living with CFS thus presents a complex and unique challenge to both the experience of identity and contemplations surrounding the future. As such, whilst acknowledging potential methodological limitations, the current findings suggest that when working therapeutically within the field, clinicians must pay greater attention towards issues of identity and expectations for the future; these being pivotal in facilitating a stance of integration, acceptance and ultimately adjustment to the illness condition.
1. INTRODUCTION

1.1 Overview of introduction

This study will explore the ways in which individuals living with Chronic Fatigue Syndrome (CFS) think about themselves, both currently and in the future. In introducing the wider context for this study, the impact of chronic illnesses upon the lives of those affected shall be summarised, before discussing psychological, post-modern and social constructionist conceptualisations of self and identity. Subsequently, the concept of 'contested' illnesses will be introduced. Here, the predominant focus will be on one specific contested illness, namely Chronic Fatigue Syndrome (CFS), with a view to considering the applicability of more generalised theories of the self in chronic illnesses, within this population. An in-depth review of both broader and specific (related to self/identity) research within CFS will then follow, identifying gaps in the current literature, thus setting the aims for the current study.

1.2 Setting the Scene: The Experience of Living with a Chronic Illness

'Chronic illness' is an umbrella term for a wide variety of illnesses and medical problems of long duration and slow progression; the initial symptoms typically being mild, non-disabling and vague. Thus the illness itself may not be easily recognisable and effective diagnostic/treatment strategies rarely exist (Stewart & Sullivan, 1982). Consequently chronic illnesses have the capacity to irrevocably change the lives of those affected. Specifically, neither the illness nor its consequences are static, both interacting to necessitate ongoing and complex management, continually challenging the sense of order and continuity within the affected individual's life (Charmaz, 1991).

Within Kathy Charmaz's (1991) extensive qualitative research, life with chronic illness emerged as being experienced in various ways. Here Charmaz undertook extensive interviews with 90 people living with a range of chronic medical conditions including: cancer; circulatory diseases; metabolic diseases and neurological conditions. These explorations were subsequently analysed using a Grounded Theory methodology, highlighting the initial experience of chronic illness as a temporary interruption with a predictable outcome (recovery), before progressing to become a more permanent factor in the person's life, which they learn to expect and attempt to control. Here, illness comes to be experienced as an 'intrusion', shifting 'bad days' and fading health hindering the ability to engage in valued

Contemplating the Future in CFS: A Grounded Theory Exploration of the Experience of Self and Contemplation of the Future Across Individuals with Chronic Fatigue Syndrome
pursuits. Life subsequently becomes founded on illness and days dissolve into attempts to weather ongoing complications and crises (Charmaz termed this ‘immersion in illness’, 1991). Individuals may fluctuate through these stages as experiences of shifting medical treatments serve to move the chronic illness from the foreground to the background of their life. However, whilst identification with individual stages varies, the associated changes to the lived experience typically render activities and roles associated with the individual’s previous existence inaccessible/changed, resulting in the experience of repeated and varied losses to the person’s previous ways of defining themselves (identity/self), Charmaz (1991).

1.3: Theoretical Understandings of Self and Identity

Before discussing the relationship between the self, identity and chronic illness, it is necessary to further consider to what we are referring when citing such terms.

1.3.1: Cognitive Understandings of Self and Identity

Within the fields of psychology and sociology, extensive attention has been paid to the concepts of ‘self’ and ‘identity’. Earlier cognitive psychological theories typically regarded the self as a static, internal construct linked to autobiographical and episodic memories comprising knowledge of our past experiences (Kihlstrom & Cantor, 1984). Here, the self can take the form of self-schemas relating to past behaviour, which in turn contribute to an individual’s self-concept (a more conscious, declarative store of stable unifying features, Block, 1981); this aggregation of various self-concepts giving rise to the sense of identity or ‘who we are’.

1.3.2: The Self as a Theoretical Map

More recently notions of self/identity have been conceptualised as representing a theoretical map, organising our past and presenting experiences (Brown, 1988, Oyserman, 2004). The ‘self’ has also been described as a more dynamic system of constructs, exerting an influence over the contemplation of the future. Indeed, the very act of thinking about the future is inextricably linked with consideration of representations of how we might go on to look, feel or act (Cantor et al, 1986). Specifically, Markus and Nurious (1987) described a multifaceted model of self, comprising many imagined ‘possible selves’\(^2\), be they ‘hoped for’ or ‘feared’.

\(^2\)Schemata representing potential/hypothetical conditions of the self.
As such, the self-concept provides a forum for attributing meaning to ourselves, drawing together subjective experiences over time (Charmaz, 1990), whilst influencing plans for the future (Karniol & Ross, 1996). Consistent with such definitions, notions of self/identity have been closely linked to self-regulation behaviours. Here, the concept of self-regulation refers to the means by which individuals engage in, or refrain from behaviour in the immediate or on-going present, in order to increase the odds of attaining self-relevant goals later. Thus our self-concepts are relevant to the things we do, feel and believe, implicitly taking into account how we wish to define ourselves; images of what we do feeding back to inform our possible futures, sketching out the possible selves we can become and the strategies necessary in achieving them (Hellstrom, 2001).

1.3.3: Understanding the Self and Identity within the Social Context

Whilst the above understandings highlight the active role of the ‘self’ in influencing both current and future existences, they omit consideration of wider social, contextual influences upon the self. This is interesting given that understanding the self in the context of social situations is not new. Indeed, in 1947, Mead described the mind and self as products of social processes. Here, Mead proposed that individual psychology was intelligible only in terms of social processes, the individual’s self, and self-consciousness of their experience, comprising both the ‘I’ (physiological/psychological aspects of self that are the subject of action) and ‘me’ (social aspects of self constituted through observing the reactions of others in response to ourselves). These distinct aspects of the self were proposed to develop in childhood following social processes (specifically spoken language/social interactions), giving rise to the individual’s sense of identity. This shift away from specific self-concepts, towards the ways in which we as humans define/differentiate our ‘selves’ in relation to others (Hewitt, 1992), led to self-concepts being conceptualised as important in negotiating integration within, the larger social whole (Onorato & Turner, 2002).

1.3.4: Post-Modern Perspectives on the Self

Whilst the above notions acknowledge the influence of the social world on the developing self/identity, they continue to imply that the self is an ‘internal’ construct, developing largely through early social interactions, exerting a static influence over behaviour. Conversely, the growth of post-modern ways of thinking (e.g. Foucault, 1988) facilitated a rejection of this inner, fixed ‘essence’ defining who we really ‘are’, such rigid and static notions of the self representing discourses as opposed to ‘truths’. Rather, the self became conceptualised as a dynamic and continuing discourse identified through shifting communications between oneself and others. Further definitions include the ‘looking glass self’ (Cooley, 1902, Yeung...
& Martin, 2003), where the self is understood as the product of our learning to see ourselves from the perspectives of others. This symbolic interactionist view stems from Mead’s early writings, focussing on humans’ responses to the perceived intent behind others’ actions, these interpretations continually modifying meanings ascribed to experiences throughout the life-span (Yeung & Martin, 2003).

1.3.5: A Social Constructionist View of Self
Symbolic interactionist understandings of self are part of a wider philosophical approach known as social constructionism, a school of thought which sees the experience of ‘reality’ as both subjective and constructed through social interaction with others. Here, the focus is to uncover the ways in which social interaction shapes the emergent and continuously shifting reality (Berger & Luckman, cited in Charmaz, 1990). As a consequence, the socially constructed reality is seen as a dynamic process, reality being reproduced by people acting on their interpretations/knowledge of it. Thus, identity is regarded as a continuously shifting construct, influenced through reflexive attempts to make sense of our own interpretations of ourselves alongside those conferred upon us by others, through the social processes of interaction (Charmaz, 1987).

1.4: The Self in Chronic Illness

Before moving on to consider social constructionist conceptualisations of the self in chronic illness, it is necessary to briefly consider wider theoretical understandings of the self in this context.

As Merleau Ponty states (1962) the body is the embodiment of who we are; the self becomes what it is through the body. Thus, when we consider this inextricable link between self and body, individuals with chronic illness can become caught in a “fateful embrace”, where what happens to one also affects the other (Corbin, 2003). As Corbin reflects, ‘people rarely say, “My body had cancer”... body and self are viewed as a unit...’, thus when the body changes the self is left unsettled and uncertain (Conrad, 1987). More specifically, Corbin and Strauss (1988) have proposed a theoretical model, highlighting the relationships between three aspects of the ‘suffering’ individual, namely the body, biography and the self. Here, the body is conceptualised as the sine qua non of the self, the resource through which individuals assimilate and divulge knowledge about the world. Alongside undertaking action, the body facilitates communication/interaction with others, speaking to them through sensations anchored in meanings derived through social experiences. These, in turn come from being

Contemplating the Future in CFS: A Grounded Theory Exploration of the Experience of Self and Contemplation of the Future Across Individuals with Chronic Fatigue Syndrome
able to look, do and experience life in ways consistent with our sense of ‘who we are’ (Corbin, 2003). As such, the experience of chronic illness represents a ‘biographical disruption’, radically changing daily life structures, necessitating a re-construction of who one ‘is’ as individuals seek to discover those aspects of the identity which have been lost, those which remain and those new aspects which have been added (Corbin & Strauss, 1987).

1.4.1: The Impact of Chronic Illness on Temporal Aspects of the Self
An additional factor influencing biographical negotiations is time, life with chronic illness raising questions about past recollections and future expectations. In social constructionist terms, the story that a person constructs about their life, past, present and future is changed (Bury, 1982), eliciting questions about where one ‘is going’ and ‘what the future holds’. For those individuals overwhelmed by feelings of grief for the lost life, the self may become rooted in, and defined by, a need to ‘recapture the past’, waiting and hoping for a return to past ways of interacting. Others may find their self rooted in the here and now, being unable to map out any kind of ‘future’. Alternatively, some people may find themselves living in silent terror as they await a dreaded, uncontrollable future associated with dependency and death or conversely consumed by a hope for a fuller realization of themselves (Charmaz, 1991).

1.5: What about Contested Illnesses?
Of course in considering such work it is important to understand that Charmaz’s (1990) findings represent a construction of her own interpretations of interviews across a broad range of chronic illnesses. Consequently, they may not necessarily reflect an external ‘truth’ relevant to all individuals with chronic illness. More specifically, the range of chronic illnesses considered by Charmaz (1991), typically associated with clear physiological/neurological underpinnings and being largely permanent in their trajectory, may have concealed variations across the illness experience, raising questions as to the applicability of such work among those individuals affected by ‘contested’ illnesses, where clear medical consensus about causes, symptom profiles and treatment are absent.

1.5.1: Chronic Fatigue Syndrome as a Contested Illness: History, Overview and Prevalence
Arguably one of the one of most contested illnesses to-date is Chronic Fatigue Syndrome (CFS), sometimes also referred to as Myalgic Encephalopathy (ME), which is a relatively

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Contemplating the Future in CFS: A Grounded Theory Exploration of the Experience of Self and Contemplation of the Future Across Individuals with Chronic Fatigue Syndrome

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22 With the exception of possible remission in some groups of the sample.
widespread, yet remarkably poorly understood condition (Gray & Fossey, 2003). CFS typically begins with a viral illness such as influenza, although onset can also be gradual (DeLuca et al., 1997). CFS has been likened to the 19th century diagnosis of Neurasthenia or nervous exhaustion, where intense mental and physical fatigue occurred in the absence of objective measurable signs of disease (Kim, 1994).

1.5.1.1: Presentation and diagnosis

Consistent with these historical syndromes, diagnosis of CFS necessitates the presence of disabling physical and mental exhaustion, not attributable to lack of motivation (Fukuda et al., 1994). However, the symptom complexes associated with CFS are diverse and unpredictable, with some individuals experiencing total disability, physical pain and exhaustion, whilst others remain physically less affected but equally consumed by experiences of forgetfulness and cognitive difficulties (Clarke and James, 2003). Symptoms can also fluctuate widely from day-to-day, or even hour-to-hour (Dougall et al., 1998). Consequently, the diagnostic criteria are broad, encompassing a variety of symptoms, which require the presence of persistent, unexplained fatigue (of new onset), not due to ongoing exertion or relieved by rest (Centres for Disease Control and Prevention criteria [CDC], Atlanta USA, Fukuda et al., 1994). In addition, four or more of the following symptoms should be present for at least six months: Impaired memory or concentration; post-exertional malaise\(^2\); un-refreshing sleep; muscle pain; multi-joint pain (without swelling/redness); headaches of a new type or severity; sore throat; tender cervical/auxillary lymph nodes.

This breadth of symptoms can cause diagnostic confusion, CFS being conceptually and diagnostically very similar to other ‘physical’ disorders such as fibromyalgia (Wilson et al., 2001). Others have suggested that CFS may be depression in another ‘face’ (Eichner 1989), due to high incidences of co-morbid depression/somatic anxiety and pre-morbid pessimism/future despair (Kroenk et al., 1988). There is also a high level of symptomatic overlap between CFS and depression including: loss of energy; fatigue and sleep disturbances, rendering it difficult to disentangle the two. However, methodological limitations (the above studies relying on questionnaire measures alone) render it difficult to disentangle whether the co-morbid mood states observed in CFS occurred prior, or in response to, it’s development. Furthermore, recent studies have distinguished CFS from depression by the absence of low self-esteem and cognitive distortions across all situations among those with CFS (Moss-Morris & Petrie, 2001).

\(^2\) Extreme, prolonged exhaustion and sickness following physical or mental activity.

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1.5.1.2: Prognosis
Consistent with the lack of clear aetiology, CFS cannot be treated or cured, management aiming to address presenting symptoms such as muscular pain/dizziness through gradual rehabilitation. As such, the prognosis varies widely, 'recovery' being generally unpredictable, with improvements spanning anything from months to years. In attempting to explore the prognosis of CFS further, Schmaling et al. (2003) identified distinctly different subgroups of chronic fatigue according to a continuum. Within this study, whilst 21% of individuals (n=100) diagnosed with CFS no longer met criteria after 1.5 years, individuals with more severe unexplained fatigue showed no significant improvement. Whilst such findings are hindered by difficulties diagnosing CFS and the need for further longer-term follow-up across larger timeframes, there is a general consensus that where recovery does occur this is most likely to be early on, with relapses remaining frequent.

1.5.1.3: Functional impairment and quality of life
As individuals live with the effects of CFS, various impacts have been observed. Specifically, deteriorations in work, study, self-care, domestic tasks, relationships, leisure and exercise are widely documented (Barrows, 1995; Pemberton, Hatcher, Stanley & House, 1994). Interestingly, such impairments have been linked explicitly with the presence of post-exertional malaise, cognitive impairments and muscle weakness and were documented as marked in comparison to both people without illness and those with other illnesses including hypertension, congestive heart failure, diabetes and multiple sclerosis (Komaroff et al., 1996; Wessely et al., 1997).

Given these impacts, it is hardly surprising that quality of life is also impaired, with low levels of life-satisfaction (assessed via subjective mood/quality of life measures) being observed Rakib et al. (2005). These quality of life impacts have also been linked to changes in interpersonal relationships, specifically the social isolation associated with frequent trivialising or disregarding of symptoms by others (Ware, 1992). Interestingly, the ways in which individuals make sense of illness can also influence quality of life, DeRidder et al. (1998) observing that self-evaluation of adaptive functioning was predictive of quality of life among people with CFS, whilst objective disease characteristics were more relevant in people with Parkinson's disease.

1.5.1.4: Illness attributions, beliefs and behaviours
The above findings necessitate exploration of social attribution theories pertaining to the ways in which individuals interpret events and the subsequent influence of these interpretations on

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their illness behaviour. Specifically, Leventhal et al (1992) developed a self regulation theory, explicating the ways in which underlying cognitive representations regarding the illness experience guide coping efforts. In doing so, Leventhal proposed that illness-related cognitions, emotions and coping efforts, stem from our underlying models of illness beliefs and knowledge. Five dimensions of underlying illness cognitions were proposed, including: identity (label and perceived symptoms of the illness); perceived cause; time-line (acute/chronic); perceived consequences (e.g. loss of independence) and curability/control (Leventhal et al, 1992). Here, with regards to CFS, Heijmans (1998) observed that explanatory beliefs regarding CFS as a serious condition (without cure), with serious consequences and beyond individual control were predictors of negative outcome in terms of functional impairment and wellbeing.

In later studies, personal responsibility correlated positively with manageability, while perceptions of seriousness correlated positively with beliefs about external causation (Heijmans & DeRidder, 1998). These findings are consistent with other studies documenting associations between attributions of CFS to biological origins (e.g. viral infections/immune dysfunction) and poorer prognostic outcomes (Ax et al, 1998; Butler et al, 2001, Joyce et al, 1997), possibly through associations with beliefs that activity may worsen symptoms (Petrie et al, 1995). Conversely, some studies have observed that individuals with CFS may also identify psychological factors associated with their condition. For example, Clements et al (1997) and Heijmans (1998) identified psychological attributions pertaining to the role of both external (wider stresses) and internal (e.g. emotional confusion) causes of CFS, some suggesting that acknowledging psychological ‘causes’ may improve prognosis (Taylor et al, 2002).²⁴

1.5.1.5: Medical attitudes toward CFS
The issue of psychological factors in maintaining CFS has implications for associated medical attitudes towards the condition. Indeed, the range of symptoms and typical failure to observe significant accompanying medical abnormalities, has raised questions about whether CFS is a valid diagnostic entity (Kim, 1994), or a ‘ragbag’ of non-specific symptoms common across the early stages of many other medical conditions (Loblay, 1995, Twemlow et al, 1997). Furthermore, as CFS is generally diagnosed only in the exclusion of other physical/psychiatric disorders, some professionals have conceptualised it as a ‘disorder of the mind’, associated with labels such as ‘psychoneurosis’, ‘bored housewife syndrome’ (Loblay, 1995) or ‘Yuppie Flu’ (Kim, 1994, Wessely, 1990). Interestingly, these attitudes persist despite research

²⁴ It should be stressed that these are statistically non-significant trends.
suggesting that GP/societal scepticism may be exerting a sampling bias impact through deterring all but the most socially advantageous from seeking help (Richman, Flaherty, Rospenda, 1994). Indeed, one large scale US community study attempted to over-come biases in access to healthcare treatment among CFS. Here, Jason et al (1999) used random telephone screening to identify individuals meeting CFS diagnostic criteria before subjecting them to further psychiatric and medical examinations. Findings observed higher incidences of CFS among middle-to-low socioeconomic groups, the lowest rates occurring in highly skilled workers. Similar findings were observed in an Australian community based study whereby incidences of CFS, as identified through medical/psychiatric screening, displayed no bias towards particular social class groupings (Lloyd et al, 1990). In addition, the increased prevalence in women may reflect heightened antibody response to viral infections (Levine, 1997) or greater requirements for women to attend medical services for routine check ups (Verbrugge, 1989).

The above attitudes may underlie current findings that as many as 48% of a sample of 811 UK based General Practitioners (GPs) did not feel confident in diagnosing CFS/ME, 41% also lacking confidence in its treatment (Bowen et al, 2005). Another recent study adopted a Grounded Theory method to analyse the transcripts of 46 UK based GPs, in response to a series of clinical scenarios involving people with either CFS or Irritable Bowel Syndrome (IBS, Raine et al, 2004). The scenarios required GPs to rate their level of agreement with the use of mental health interventions, before meeting for a facilitated discussion exploring differences in opinion related to the scenarios. Analysis noted that some GPs tended to see individuals with CFS as having “a certain personality trait that is CFS waiting to happen”. More specifically, the changing diagnostic labels associated with CFS also served to de-legitimise the condition, as did the lack of specific anatomical location. Whilst individuals with CFS were seen as ignoring the “sick role” obligation to get better as quickly as possible, individuals with IBS were seen as “battling through” and rarely missing work. GPs also described difficulties managing CFS as a condition, describing it as being like “groping in the dark” or as a “burden”, one stating “I would rather treat a whole surgery full of people with Irritable Bowel Syndrome than people with Chronic Fatigue”.

Of course these quotes represent only isolated excerpts from the several, four hour, focus groups undertaken within the study. Furthermore, as with all qualitative research, the selection of themes will always be filtered to some extent through the lens of the researchers. As such, the authors’ decision to compare CFS with IBS, rather than a more

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25 Using the Fuduka criteria discussed previously.
serious/complex physiological illness may have exacerbated the polarisation of opinions (A. Kennedy, personal communication, British Medical Journal in response to Raine et al, 4th June 2004). However, a further communication in response to the article highlights the very ‘real’ and ongoing controversy associated with CSF:

“Anyone who has dealt with these patients for any length of time knows that a high proportion of them have had deeply dysfunctional lives prior to their ‘illness’. The secondary gain associated with medicalising what is a psychological condition is immense, and leads to frustration on the part of a patient and doctor...I believe that in a future DSM chronic fatigue, anorexia, bulimia and chronic pain will all be included under ‘Personality Disorders’ section.” (B. Johnson, personal communication, British Medical Journal in response to Raine et al, 4th June 2004).

1.5.1.6: Dominant discourses surrounding CFS

The above controversy can be understood as socially constructed through the interactions of people living with the condition and medical professionals/wider society at large. Here, interactions between people with CFS and the medical profession frequently take the form of vigorous debates, often centring on the process of diagnosis and diagnostic labelling. This is perhaps not surprising when we consider that labels reflect socially constructed meanings. Specifically, advocacy groups have criticised the use of the label ‘CFS’, believing that it trivialises suffering associated with the condition, contributing to negative attributions (Fitzpatrick, 2002; Stein, 2001). As such, when assessing individuals labelled with ‘ME’ as opposed to ‘CFS’, medical students’ attributions depicted a poorer prognosis and underlying physiological, as opposed to physical (Jason et al, 2001). In this regard it has been argued that the label ‘CFS’ may be associated with a minimisation of illness effects and wider stigmatization (Jason & Taylor, 2001). Consequently, within the US, attempts have been made to enhance illness credibility and minimise psychiatric connotations through re-labelling the condition as CFIDS (Chronic Fatigue Immune Dysfunction Syndrome, Leitch, 1995).

1.6: The Experience of the Self/Identity in CFS

Given the unique impact of CFS upon the lived experience and associated controversy/debates surrounding its validity, it is necessary to consider whether CFS may also uniquely influence the identities of those affected. To date there have been few studies exploring the nature of self and identity in people living with CFS. In 2000, Aspring described how 25 Swedish women with CFS and fibromyalgia (a similarly contested condition, typically associated with
lesser levels of fatigue and greater experiences of muscle pain) came to terms with their newly arisen identities. This study adopted a symbolic interactionist approach, outlining the 'biographical work' undertaken as individuals struggled to reconcile their identities and highlighted a number of phenomenological themes, including experiences of loss as the extensive social consequences (e.g. inability to work) associated with the way in which CFS challenged tendencies to define the self by work and social connections.

A further study of identity in CFS undertook a discourse analysis of the text transcripts of interviews with 59 individuals (comprising a mix of men and women) with CFS (Clarke & James, 2003). Like Aspring, this work identified a narrative of adjustment over time. Here, again loss of self was emphasised, as was the sense of disaffection and separation from their former lives. However, Clarke and James went on to further explicate the processes associated with the social consequences of CFS. Specifically, they noted how, over time, individuals described developing a 'calculus' of friends and family, only some of whom had remained loyal, this resulting in shifting evaluations of relationships and at times, further experiences of loss and rejection.

Whilst Aspring’s research largely neglected any consideration of the impact of the contested status of CFS, Clarke and James emphasised the role of wider power discourses in describing the ways in which individuals stepped outside their former lives because of embarrassment when their definitions of illness were questioned. As individuals were increasingly confronted with the loss of the former self, functioning, friends and even a legitimate place in society, the development of a new 'radicalised' self was documented. Here the radicalised self reflected a ‘new self’ valued more than the previous identities and was not accompanied by a desire to return to previous ways of functioning. Instead, this radically different consisted of changed values and a capacity to look at the 'big picture' with regards to the meaning of life. The development of this new sense of self was related to the absence of a legitimizing discourse (viewing illness as a temporary and 'medical' condition), thus necessitating the development of an alternative identity, where the individual is radicalised as a new kind of autonomous, responsible and self-governing citizen (consistent with, Robertson, 2000).

1.6.1: Gaps in the Current CFS Evidence Base

Whilst the above research provides an enlightening account of the ways in which individuals with CFS experience changes to their sense of self, it gives little consideration to the ways in which individuals think about their futures and the types of people they may wish to become. Given the inextricable influence of identity on expectations for the future within both

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traditional psychological theories of self/identity and the social constructionist writings of the self in chronic illness, this oversight would suggest a failure to consider a potentially important aspect of the experience of living with CFS.

Indeed, similar research questions have been applied to the condition of ‘chronic pain’ (Hellstrom, 2001). Here, ‘chronic pain’ is a broad term referring to the subjective experience of pain over prolonged periods, which for some, but importantly not all individuals, occurs in the absence of clear underlying pathology. To this extent, for some chronic pain may also be experienced as a contested illness, making this research of relevance to the current debate. Here, Hellstrom’s work aimed to explore chronic pain patients’ conceptions of the self, paying particular attention to temporal influences and thoughts about the potential future. Findings suggested that many individuals experienced their ‘self’ as imprisoned by the body, entrapped within a slowly passing ‘present’ unable to contemplate future plans, preparations or identities. Where future identities were described, these were referred to as ‘hoped for’ and ‘feared selves’, which in turn posed important consequences for adjustment to the chronic pain condition. Specifically, perceived possibilities were often curtailed or associated with ‘feared’ selves, which when not coped with by avoidance or denial, were often a source of great anxiety. Conversely, ‘hoped for’ selves also elicited distress through being characterised by lowered ambitions.

Here, Hellstrom moved beyond the explication of these constructs towards outlining relationships with the process of adjusting to the illness condition. Specifically, the absence of future identities or ‘possible selves’, or the presence of negative self-conceptions projected onto the individual from others (e.g. work-shy/lazy), was proposed to hinder self-regulate behaviours necessary in facilitating more ‘adaptive’ ways of functioning. By contrast, where ‘positive’ possible selves existed, these appeared to represent strong motivational force in promoting health-behaviour and adjustment.

Whilst chronic pain is in many ways similar to CFS, the experience of chronic pain can also be associated with a range of less contested medical illnesses, such as arthritis. In addition, the symptoms of chronic pain are sometimes more amenable to medical management than those of CFS, where the nature and intensity of symptoms can fluctuate more widely. It is, therefore, necessary to explore the extent to which the above literature remains applicable for individuals with CFS. As such, the aim of the proposed study is to generate a theoretical understanding of how people living with Chronic Fatigue Syndrome (CFS) experience thinking about the future and the ways in which they conceptualise their sense of both who

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they are, and who they may become (identity), over time. In doing so it is necessary to consider the ways in which external factors shape and influence these processes, this work being important in informing professional understandings of the experience of CFS and the way in which future goals and identities are acknowledged, validated and addressed within therapy.

1.7: Aims of the Current Study

The overall aim of this study is to generate a theoretical understanding of the experience of, and processes influencing, the contemplation of the future and future identity goals, for people living with CFS. As such, the specific aims of the study are to explore:

- The ways which people with CFS currently see/define themselves (their identity).
- The ways in which individuals living with CFS experience thinking about their future and who they may become.
- The types of expectations held about the future and future identities.
- The extent to which these expectations and future identities have changed/remained the same since developing CFS and factors important in influencing this process.

2. METHODOLOGY

This chapter presents an overview of the reasons for undertaking a Grounded Theory methodology in addressing the studies aims, before providing a detailed description of the associated procedures.

2.1: Selecting the Appropriate Methodology

The current study aimed to undertake a detailed, rich exploration of the ways in which individuals with CFS think about themselves and their futures, as opposed to finding observable ‘facts’ or ‘truths’. This rendered it ideally suited to the qualitative paradigm, whereby the researcher attempts to ‘indwell’ and become the instrument for data collection, capturing the multifaceted and complex elements of human experiences/activity (Maykut, 1994; 27). The exploratory nature of qualitative methodologies is also suited to researching into sensitive areas (Walker, 1995) such as chronic and contested illnesses (Charmaz, 1991). Furthermore, given the lack of research pertaining to issues of temporal aspects of the self in Contemplating the Future in CFS: A Grounded Theory Exploration of the Experience of Self and Contemplation of the Future Across Individuals with Chronic Fatigue Syndrome
CFS, a qualitative methodology was felt suited towards facilitating the exploration of issues where there were few ‘hypotheses’ to be tested (Strauss & Corbin, 1990).

2.2: Why a Grounded Theory Approach

As the current study sought to generate a theory accounting for the experience of contemplating the self and the future in people living with CFS, a Grounded Theory methodology was adopted because of its use in facilitating the development of new theories and hypotheses. Developed by sociologists Glaser and Strauss in 1967, Grounded Theory originated as a form of systematic, qualitative, analysis, associated with its own unique logic and practical guidelines, differing from other qualitative approaches in that researchers use their emerging theoretical categories to shape the data collection whilst in the field (Charmaz, 1990), generating a theory ‘grounded’ in the research situation ‘as it is’, rather than a reproduction of pre-existing concepts.

2.2.1: Philosophies informing Grounded Theory approaches

Initially Grounded Theory was deemed as a somewhat positivist approach, by virtue of its supposedly ‘inductive’ research stance, advocating a distancing of the researcher from relevant literature, until after theory generation. However, over time some (Henwood and Pidgeon, 1996, Charmaz, 1990) have questioned whether such separation from the research process is necessary (Oliver, 1992). Consequently, the researcher’s role as a passive observer of an external reality has been questioned, facilitating an integration of Grounded Theory methodologies alongside more hermeneutic, symbolic interactionist (Clarke & James, 2003) and constructivist approaches (Charmaz, 1990, 2006). What follows has been a move towards exploring an emergent reality, fundamentally shaped by social interaction (Charmaz, 2006). Here, the researcher fosters a reflexive stance acknowledging their active role in shaping both the process and product of the research, culminating in the creation of a theory that is generated through an interaction between the researcher, population sample and the data.

2.3 Reflexivity

Given the influence of one’s own epistemological stance upon the choice of research question and methodology, I shall now consider my own stance as the primary researcher within this study.
As a trainee Clinical Psychologist, and prior to that an Assistant Psychologist, I have witnessed a shift in emphasis towards the inclusion of more reflective/reflexive stances alongside more traditional positivist research methodologies. Where once psychologists were viewed largely as applied scientists bound to the generation of evidence-based practice, my training experiences have led me to believe that a more critical mode of operation now exists, whereby there is an increasing emphasis on reflecting upon our own actions within/responses to, our therapeutic work, alongside a questioning of what constitutes ‘evidence’ (consistent with Lavender, 2003). Such a stance possibly reflects a growing recognition of the role of Clinical Psychology. Consequently, whilst evidence based practice still holds an important place in research, there may be a reduced need to lay claim to a knowledge base supported by positivist science (Schon, 1983, 1987).

Within my clinical practice, these changes have resulted in a continual emphasis on ‘reflective practice’, by which I refer to the process of reflecting (cognitively and emotionally) on what I am doing, why and what I should do next (Lavender, 2003). This shift has accompanied a widening of the predominantly cognitive behavioural focus of teaching, towards inclusion of systemic approaches allowing the clinical interview to become a forum for unpacking subjective experiences, meanings and processes. Consequently, I am continuously aware of my own influence within my therapeutic work and have developed an interest in the ways in which individuals come to understand and add meaning to their lives. As such, I find myself naturally leaning towards phenomenological and constructivist epistemologies in an endeavour to explore the ways in which individuals make sense of their own unique experiences. Thus for me, any research interview will inevitably reflect a mix of my own ideas about what it is relevant to explore and my past experiences related to the research question.

I found this stance especially relevant to the current study as my interest in the research question followed from my previous training experiences. Specifically, within my first year, I worked within a specialist Health Psychology service, co-facilitating a psycho-educational group for individuals living with CFS. In doing so I was struck by the emotive reactions elicited by questions about the self and future, which even extended towards attempts to set meaningful goals to be achieved across the course of therapy; this process necessitating the capacity to reflect upon a life where illness may be ongoing. Whilst I was left curious as to what issues these questions raised, I was torn as to how to raise such sensitive questions within further research and chose to discuss the project idea with service users with CFS who
described that issues of 'who they are'/'who they may become' were both central and emotive aspects of their daily lives.

I subsequently became keen to understand more about the experience of thinking about the self and future in CFS. However, equally I was concerned not to let these prior experiences pre-conceive the research process, being aware that my position as a young professional female (without CFS) would undoubtedly shape the stories shared regarding their experiences and my interpretation of them. Thus the culmination of these factors, alongside my unfolding experiences as a 'reflective practitioner' through training, rendered me drawn towards social constructionist ways of working, which allowed me to acknowledge and guard against, forcing the data along lines that would inadvertently confirm my own previous experiences with individuals with CFS.

2.4: Recruiting Participants

2.4.1: Sample Size

Whilst planning to recruit a dozen individuals with CFS (including both men and women of a variety of ages) due to time constraints it was only possible to interview seven\(^{26}\). Here, it was recognised that an 'ideal' sample size for qualitative research remains a contested issue (Charmaz, 2006), with the number of participants typically being inversely related to the richness of the data (Morse, 2000); sample sizes for qualitative studies typically range from 7/8 (for studies based on experiential/phenomenological issues) to 60 for large scale Grounded Theory studies). Indeed, sample sizes as small as 6 have successfully been utilised within qualitative research (Howes \textit{et al}, 2005). Consequently, although the current study utilised a Grounded Theory methodology (typically necessitating larger sample sizes) its focus on gaining focussed, rich, experiential data from a selected group of key informants, facilitated the use of a smaller sample. The use of a constructivist perspective also meant that attempts were not being made to identify observable truths, which would have necessitated the use of a larger sample size in producing a 'generalisable' theory.

2.4.1: Demographic Information

Consistent with other qualitative research studies (Aspring, 2001) there was a need to collect some background information to inform understandings of the wider sample context (Charmaz, 2006). As such, a basic demographic details questionnaire was constructed,

\(^{26}\) Although the researcher is endeavouring to undertake a further interview between the current date and Viva.
collecting information from each of the participants on: age; ethnicity; relationship circumstances; educational/employment history; duration of CFS and previous treatments (see Table 1 for results and Appendix, 5 for questionnaire). Participant ages varied from 24 to 65. All participants described themselves as White-British; all but one was married, co-habiting or in a relationship. Most had accessed a wide range of therapies (conventional and complementary) prior to attending the group from which they were recruited. Only one participant (Samantha) was currently within employment and this was fulltime in nature.

27 With the exception of Lucy who did not return the demographic details questionnaire and subsequently suffered a relapse. A decision was made by the referring clinician that it would be inappropriate to contact her for this information. Subsequently, relevant demographic information was collected from Lucy's interview instead.
### Table 1: Participant demographic information.

<table>
<thead>
<tr>
<th>Participant Number</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Participant Pseudonym</strong>&lt;br&gt;(age range)</td>
<td>Margaret (50-55)</td>
<td>Emily (20-25)</td>
<td>Lucy (25-27)</td>
<td>Rose (50-55)</td>
<td>Jim (50-55)</td>
<td>Peter (60-65)</td>
<td>Samantha (25-30)</td>
</tr>
<tr>
<td><strong>CFS onset</strong></td>
<td>5-10 years previously</td>
<td>+10 years ago</td>
<td>1-5 years ago</td>
<td>+10 years ago</td>
<td>1-5 years ago</td>
<td>+10 years ago</td>
<td>5-10 years ago</td>
</tr>
<tr>
<td><strong>Highest Academic Qualification</strong></td>
<td>Post Graduate Qualification</td>
<td>O-Level/A-level</td>
<td>O-Level/A-level</td>
<td>Degree</td>
<td>None</td>
<td>NVQ/Diploma</td>
<td>Post Graduate Qualification</td>
</tr>
<tr>
<td><strong>Occupation Prior to Developing CFS</strong></td>
<td>Academic/Managerial</td>
<td>Student (School)</td>
<td>Public Sector Managerial Role</td>
<td>Senior Academic/ Management</td>
<td>Clerical/Managerial</td>
<td>Skilled Professional</td>
<td>Student (University)</td>
</tr>
<tr>
<td><strong>Current Occupational Status</strong></td>
<td>Unemployed</td>
<td>Receiving disability benefits</td>
<td>Receiving disability benefits</td>
<td>Receiving disability benefits</td>
<td>Receiving disability benefits</td>
<td>Receiving disability benefits</td>
<td>Working Full-Time</td>
</tr>
<tr>
<td><strong>Current Relationship Status</strong></td>
<td>Married</td>
<td>In a relationship but not cohabiting</td>
<td>Single</td>
<td>Married</td>
<td>Married</td>
<td>Divorced</td>
<td>Cohabiting</td>
</tr>
</tbody>
</table>
2.4.1.1: Selection

Participants were recruited from a self-management group for CFS within a specialist Health Psychology service in the south of England.

Inclusion criteria

All participants:
- Had a diagnosis of CFS from their GP/other professional (CFS duration of at least 6 months).
- Were able to converse fluently in English (due to the nature of the interview based method).
- Were on the caseload (current or past) within the specialist psychological therapies clinic. This included participants who had attended previous psycho-educational groups at the centre, providing they were in ongoing contact with the service through regular follow-up groups.

Patients who were awaiting future groups were only approached to participate in the study if they had already been assessed for the group, or were undertaking individual work within the service.

Exclusion criteria

- Due to the definition of the research problem, participants without a formal diagnosis of CFS were not be recruited into the study.
- Similarly, due to the need to develop a theory encapsulating the experiences of individuals with CFS, individuals with other co-morbid medical diagnosis were not be recruited into the study.

Co-morbid depression/anxiety was not an excluding factor for the study. This followed an acknowledgement of the high rates of anxiety/depression experienced among individuals with CFS alongside overlap between the symptom groupings and the likely incidence of such difficulties within a sample of individuals attending a Specialist Psychological Therapies service. Whilst it was acknowledged that incidences of depression may influence conceptualisations the interview content, especially conceptualisations of the future (by virtue of feelings of hopelessness associated with low mood), it was felt that screening for, and excluding individuals on the basis of such experiences would render the population non-typical of the research situation, thus limiting the usefulness and clinical relevance of any findings gained.

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2.4.2.2: Recruitment procedure

Potential participants were informed about the study by the clinician running the groups, before being given/sent information sheets (Appendix 1) explicating the process of opting in. The researcher subsequently contacted participants to arrange a home-based interview.

2.5: Developing a Semi-Structured Interview

The interview schedule (see Appendix 6) was designed to comprise a mix of informational, reflective, 'feeling' and 'ending' questions (consistent with Charmaz, 2006). Informational questions were placed near the beginning to bring the respondent further into the interview by establishing a brief chronology of their CFS and its impact upon the lived experience. Reflective and 'feeling' questions, exploring the research aims followed, with the expectation that the researcher would then have established the necessary trust/rapport to raise such issues. Here, whilst traditional Grounded Theory approaches suggest that the researcher enters the area of study without prior conceptions (Glaser & Strauss, 1967), it was recognised that researchers would and should, have some broad questions in mind (consistent with Jones, 1985 pg 47). As such, although interview questions were pre-supposed to facilitate exploration of issues pertaining to self and the future, these questions were constructed so as to elicit respondents' stories with minimal framing (Charmaz, 2006). Conversely, the final questions were deliberately positively framed, in order to accomplish a positive closure to the interview (Charmaz, 1990). Although a 'pilot' interview was undertaken to provide feedback regarding the feasibility of the interview format, in the absence of any concerns being raised, the schedule remained unchanged until the process of theoretical sampling began (see section 2.7.2.4).

2.5.1: The Research Interview

All interviews were conducted directly by the researcher, were tape recorded and lasted approximately 90 minutes.

2.6: Ethical Issues

Care was taken to ensure that participants felt no obligation to participate and remained aware of their right to withdraw at any time, without their future care being affected. The researcher also provided regular opportunities for participants to discuss the study, prior to committing themselves. In doing so, the method for collection/storage of the data was made explicit (both...
verbally and within the consent form, Appendix 4), as were the boundaries of confidentiality and processes for resolving any distress elicited through the interview process.

Given the unpredictable nature of CFS, the researcher allowed participants to: opt for a telephone interview (not taken up by any participants), therefore reducing demands associated with a face to face interview; complete the demographic details questionnaire after the interview had ended and if necessary after the interviewer has left, returning the form by post and ensuring that participants were able to undertake regular breaks within the interview process.

2.7: Data Analysis

Grounded Theory analytic procedures most in keeping with both the sample population and constructivist nature of the study's aims were selected in analysing the data (consistent with Charmaz, 1990; 2006).

2.7.1: Transcription

As a pre-cursor to the analytic process the researcher transcribed each interview verbatim, before transferring each transcript into a computer-based qualitative analysis programme, to facilitate researcher immersion within the data and ongoing flexibility and fluidity whilst undertaking the coding processes described below.

2.7.2: Open Coding

The data was subsequently analysed using an open coding method of constant comparative analysis, identifying, naming and categorising the phenomena within the data without applying pre-conceived codes (Glaser & Strauss, 1967). Initially this was undertaken on a line-by-line basis, breaking the transcript into individual datum. This process ensured that the researcher stayed close to the data, thus avoiding unjustified conceptual leaps/assumptions (Charmaz, 1990). Whilst this initially led to the development of somewhat clumsy or awkward coding labels, this process ensured that the labels fitted the phenomena under description (see Appendix 8 for an example of a coded transcript). It also encapsulated central actions/processes within each transcript, as opposed to merely describing 'themes' within the data, thus being more in keeping with constructivist Grounded Theory approaches (Charmaz, 2006).

28 These changes followed service-user consultation in planning the study.
29 This is in contrast to most qualitative research methodologies where transcription/analysis takes place post-data collection.

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2.7.2.1: Developing focussed codes

After coding three interviews, the researcher was faced with a mass of 'line-by-line codes' many of which recurred in similar forms throughout the interview transcripts. Subsequently, the researcher engaged in a more focussed coding procedure, whereby the most significant and/or frequent earlier codes were utilised in sifting through subsequent data. Here, each paragraph of the transcript was analysed and the most pertinent line-by-line codes selected. Using the qualitative software package codes were clustered into an index system of broad categories according to the experiences/topics to which they related (e.g. thinking about the future, describing self change). After subsequent amendments were made to the interview schedule in light of these emerging categories (described in section 2.7.2.4 below), the process of line-by-line coding continued for a further three transcripts, comparing these with the pre-existing focussed codes, to ensure that the categories emerging from the data were not prematurely preconceived/ 'closed down' on the basis of the initial three interviews.

2.7.2.2: Building conceptual categories

After identifying descriptive clusters, emerging categories were raised to a more conceptual level through generating analytic or 'researcher' categories (see Appendix 15 for examples of emerging categories). By adopting a 'flip-flop' approach, shifting between the data and the emerging conceptualizations, clusters of focussed codes were slowly raised into more abstract conceptual categories. New and previously collected incidents of data were then compared to these concepts until 'core' categories emerged. These were then described in terms of their properties, noting the conditions under which they arose (consistent with Charmaz, 1990, 2006) and identifying linkages between categories to be explored across subsequent interviews.

2.7.2.3: Memo-writing

Within this process, memos were used to break the categories into components, elaborating the codes and clarifying any conceptual leaps made. Emerging ideas were subsequently explicated, the researcher engaging in an ongoing self-dialog with emerging curiosities and hunches within the data (Charmaz, 1990 [see Appendix 16 for examples of memos]).

2.7.2.4: Asking questions or theoretical sampling

In developing categories, the researcher began to 'ask questions' of the data identifying gaps/curiosities to be explored through subsequent data collection by amending the interview schedule and seeking out further participants who would deepen the emerging theory (Charmaz, 1990; Glaser and Strauss, 1967; Glaser, 1992, Strauss and Corbin, 1990). As such,
where categories had become saturated and were no longer yielding new information, the emphasis of subsequent interviews was to collect data addressing the curiosities identified within the memos. For example as shown in Appendix 15, after the first analysing three interviews, codes had emerged regarding the tendency to question illness validity and separate illness from the body. Subsequently the interview schedule was amended in order to yield further information on this curiosity. Here, rather than asking direct/closed questions directly explicating emerging hypotheses, care was taken to ensure that any amendments remained broad and not leading. Thus as can be seen from Appendix 7, the majority of amendments were small and tended to comprise prompts that the researcher would remain mindful of and introduce only when the relevant issues had emerged within the interview; thus ensuring minimal framing of the data.

2.7.2.4: Selective coding
Consistent with Charmaz (2006) and Strauss and Corbin (1990) the seventh (final) interview was selectively coded, whereby the new data and emerging relationships were compared against the emergent categories, paying less attention to any unrelated emerging/existing categories. Subsequently, the final categories were compared and contrasted against each interview in isolation, exploring the degree of fit between the emerging theory and individual narratives.

2.7.2.5: Avoiding pre-conceptions
Throughout the data analyses care was taken to ensure that the theory did not simply reflect the researcher’s own concerns, ensuring a close fit between the theory and the data through use of: methodological thoroughness with regard to the systematic analysis of the data; the use of a reflective journal to record and reflect upon the researcher’s thinking/decision making processes and regular supervision from research supervisors. Specifically, as the researcher was familiar with the work of Charmaz (which relates to similar questions of self/identity within chronic illness) and had also developed her own prior ‘hunches’ about the research situation, care was taken to explicate such prior knowledge from the outset. This ensured that evidence in support of these assumptions or ‘hunches’ earned its way into the emerging theory (consistent with Glaser 1978), rather than steering the analytic process from an unconscious or hidden level.
2.8: Evaluating Grounded Theory

To ensure the quality of emerging Grounded Theory, various criteria for evaluation were identified. Specifically, the researcher opted to integrate the criteria of Henwood & Pidgeon (1992) and Charmaz (2006). Criteria taken from Henwood & Pidgeon included the extent to which the analytic categories ‘fit with the data’. Consequently the researcher made clear links between the data and each stage of category generation, through the use of memos. The researcher also took care to identify and remain alert to her own ‘reflexive role’ in the research process, as documented above. Similarly, memos were used to justify and document the analytic process of building the theory, clearly explicating cases/incidences which ‘do not fit’ within the data and recording the emergence of hunches and categories (see Appendix 16).

In addition to Henwood & Pidgeon’s criteria, Charmaz’s notions of originality (the extent to which categories are fresh and reveal new insights) and resonance (the extent to which categories portray the fullness of the studied experience, revealing both explicit and taken-for granted meanings) were kept in mind throughout the project. However, consistent with Charmaz, a lesser emphasis was placed on Henwood and Pidgeon’s criteria of data transferability across various contexts and populations, consistent with the constructivist nature of the current project (i.e. that it developed through a unique interaction between the researcher and participants), limiting the extent to which such findings could be generalised across other CFS populations.

3.1:2 Establishing saturation

When discussing Grounded Theory, researchers typically refer to the concept of saturation as a major benchmark for evaluating their work. Whilst Glaser (1978) regards saturation as the process of comparing incidents until no new properties of the pattern emerge, Charmaz (2006) stipulates the importance of gathering data until fresh data no longer sparks new theoretical insights/properties of the core theoretical categories. However, in the context of multiple and infinite ‘realities’ these understandings mean that Grounded Theory inevitably has the potential to continue indefinitely, new perspectives on the data being continually possible (Glaser & Strauss, 1967). As such, given the time and sampling constraints of the current study, saturation was seen as a function rather than goal (consistent with Willig, 2001). Consequently, whilst saturation in the strictest sense was not possible, it was possible to saturate the existing data (and thus the research situation) within the current sample, until no further categories or properties were emerging.
3. RESULTS

3.1: A Note on the Interpretative Process

In undertaking the interviews a wide range of participant experiences were disclosed, encompassing illness biographies from the onset of, and prior to, CFS through to the time of interviewing. Participant histories were lengthy and non-linear, frequently shifting between different time points and perspectives. Whilst these narratives produced a wealth of data, consistent with the initial research questions, the analysis centred on constructions pertaining to a shifting sense of self in CFS, exploring the negotiation of such experiences and identified relationships with contemplation of the future. Subsequently, a series of core categories and associated sub-categories were identified (see Table 2 and Appendix 9, for further detail).

3.2: A Foreword Regarding Presentation

In presenting the emerging categories and theory, the processes associated with each major category will be explicated through use of participant quotes (each coded using a pseudonym) and researcher interpretations. Within the text, subcategories will be referred to using italics, whilst pertinent exemplifying focussed codes are referenced using underlined text. Here, it is important to acknowledge that not all participants identified with each sub-category, rather individual sub-categories represent elements of an overall continuum of process. Throughout the results care will be taken to highlight and explore cases where sub-categories appear less relevant. In doing so, consistent with a social constructionist/constructivist approach, the researcher has preserved the use of participant understandings related to issues of the future and self, whilst remaining curious about the construction and development of such terminology. For all categories, a detailed breakdown of associated quotes can be found in Appendices 10-14.
Table 2: Core categories and associated sub-categories identified through the analysis.

<table>
<thead>
<tr>
<th>MAJOR CATEGORIES</th>
<th>SUB CATEGORIES (1)</th>
<th>SUB CATEGORIES (2)</th>
</tr>
</thead>
<tbody>
<tr>
<td>BECOMING UNWELL</td>
<td>EXPERIENCING MULTIPLE SYMPTOMS</td>
<td>EXPERIENCING IMPAIRMENT</td>
</tr>
<tr>
<td></td>
<td>EXPERIENCING ACTIVITY</td>
<td>EXPERIENCING CHANGED RELATIONSHIPS</td>
</tr>
<tr>
<td>CFS AS A CHALLENGE TO IDENTITY</td>
<td>LOSS</td>
<td>CONFLIT</td>
</tr>
<tr>
<td>MAKING SENSE OF ILLNESS</td>
<td>QUESTIONING ILLNESS</td>
<td>QUESTIONING AGENCY</td>
</tr>
<tr>
<td></td>
<td>FEELING MISUNDERSTOOD; JUSTIFYING ILLNESS</td>
<td>BEING MISUNDERSTOOD; ASPIRING INABILITY</td>
</tr>
<tr>
<td>NEGOTIATING RESPONSES</td>
<td>DISTANCING</td>
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<tr>
<td>WILLINGNESS TO CONTEMPLATE THE FUTURE</td>
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<td>CONFLICT BETWEEN CURRENT EXISTENCE AND FUTURE PLANS</td>
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<tr>
<td></td>
<td>CONSIDERING ALTERNATIVE FUTURES</td>
<td>FUTURE PLANS</td>
</tr>
</tbody>
</table>

Contemplating the Future in CFS: A Grounded Theory Exploration of the Experience of Self and Contemplation of the Future Across Individuals with Chronic Fatigue Syndrome
3.3: **Becoming unwell: The Context for Shifting Identities within CFS**

Before beginning to consider the ways in which CFS is associated with shifting understandings of the self and the future, it is necessary to summarise the central aspects of the experience of developing CFS. Here, as it is beyond the scope of the current study to consider the processes associated with becoming unwell in detail, the central elements emerging from this part of the analysis will be *briefly* summarised, thus providing a context for the ensuing explorations of self-illness changes/contemplation of the future. Readers wanting to explore further subcategories/quotes associated with the processes of becoming unwell are referred to Appendix 10.

### 3.3.1: Experiencing Multiple and Varied Symptomatic Experiences

In exploring the experience of becoming unwell, it emerged that the onset and development of CFS whether gradual, or preceded by a sudden viral illness, presented people with a plethora of symptomatic experiences, including: fatigue, headache, muscle pain, dizziness and, in one case, tinnitus. These experiences were often constructed as occurring in parallel with one another with the resultant effect of large scale disruption to the ability to undertake activity ('illness disrupting activity').

### 3.3.2: Experiencing Uncertainty

Aside from the nature of symptoms experienced, perhaps the most powerful category to emerge was the notion of uncertainty. Here, experiences of symptomatic uncertainty were clearly constructed around the capacity to undertake activity, this becoming a benchmark for judging symptom intensity. Exploration of constructions of uncertainty highlighted a number of influences. Primarily, shifting symptoms gave rise to feelings of ambiguity about the possible illness trajectory, through repeated doubts about illness prognosis ('ambiguity surrounding prognosis'). These doubts were intensified by mystery surrounding the cause of CFS ('uncertainty about illness onset/cause') and difficulty identifying a clear point of illness onset, by virtue of insidiously developing symptoms and uncertainty during the diagnostic process (from both the individual and professionals). Secondly, it emerged that symptomatic improvements, even where sustained over long periods were constructed as highly precarious in nature and frequently experienced as being prematurely curtailed. Here, notions of worsening symptoms were closely linked to activity, as individuals frequently constructed uncertainty with regards to the cost of activity ('paying an uncertain price for activity'), whereby activity was experienced as associated with the unknown and uncertain entity of symptomatic payback. Thus in an existence dominated by ambiguity, the experience of
uncertainty paradoxically becomes the predominant certainty around which the illness experience is understood.

3.3.3: Experiencing Changed Relationships
In addition to these symptomatic experiences, individuals typically experienced significant changes within their personal relationships. Primarily a ‘loss of contact with others’ emerged as a key construct, both through the impact of physical and cognitive symptoms on hindering the capacity to engage with social activity and additionally through experiences of being abandoned/rejected by others in response to the onset or disclosure of illness. CFS was also constructed ‘as impinging upon the lives of others’ through the impact of reliance and dependency on others (for emotional/physical support) in constraining their actions. These shifts were typically constructed as being associated with feelings of guilt, which for some reflected feelings of being indebted to others.

3.4: Experiencing Self-Illness Conflict

Across participant narratives, it emerged that becoming unwell and living with CFS, presented individuals with a significant challenge to their sense of ‘who they are’, typically accompanied by feelings of ‘loss’ and ‘confusion’, associated with a ‘shifting sense of self’.

Margaret: Um, the only way to explain it is to say that, you lose yourself.

Rose: Yes, I just think I’m thoroughly confused about what kind of person I am really.

Here, this shifting sense of self was typically characterised by varying degrees of conflict between the illness experience and the pre-illness self, rendering it necessary to explore the ways in which individuals constructed the self before illness onset.

3.4.1: Construction of the Pre-Illness Self
In describing the pre-illness self, individuals generally defined themselves through their capacity for activity, both mental (concentration, ‘intelligent’ thought/conversation) and physical, frequently referring to a productive ‘doing’ capacity pre-illness.

Samantha: I was very active and I had lots of friends I enjoyed doing stuff I’ve always been a ‘doing’ person.
Margaret: *I had a real ability to concentrate for many hours, um, because I was very focussed and I could, say I’m here I want to go there and I would just do it.*

Here, whilst constructions of the pre-illness self typically focussed on career based activities\(^3\)⁰, the underlying construction seemed to flow from a sense that the pre-illness self was an active, productive being, regardless of the context.

### 3.4.2: CFS as a Conflict to the Activity based Pre-Illness Construction of Self

By contrast, explorations of the ‘shifting sense of self’, highlighted how the attributes most valued and emphasised within the pre-illness self (work, hobbies, family and social roles) became constructed as increasingly inaccessible:

Margaret: *I couldn’t do the ‘doing’, if you see what it is, um, I couldn’t concentrate a lot of the time you just don’t care, I mean you care, but you don’t care enough, that’s how it feels like, it feels, it’s almost like it feels like you lost yourself.*

Jim: *Oh it’s the ability to be yourself, I can only do certain things, I can’t just go and do what I want to do I have to think about it all the time whereas before, as I say, I was quite sporty, kind of get up and go.*

Whilst these conflicts were often constructed through a diffuse clash between illness and the capacity to undertake activity (particularly employment), some individuals articulated an underlying conflict between illness and the values enacted through activity. For Rose and Margaret, cognitive symptoms conflicted with the importance of mental activity within the pre-illness self (intelligence, sociability and academia), whilst Lucy articulated a conflict regarding the importance of independence; the enforced dependency of illness challenging those fundamentally significant aspects of her ‘self’:

Rose: *Because I know I’m an intelligent person and yet I know that these days I can come across as somebody incredibly stupid and I find that distressing.*

Lucy: *I don’t know - it’s when you have your independence and then you start to lose it even when it’s just silly things that you wouldn’t normally notice, it means a lot.*

\(^3\)⁰ All but one participant having experienced pre-illness employment.
As such, through the experience of developing CFS with its associated uncertainties and shifting contexts, illness often came to be experienced as blocking the 'true' self within ('being constrained by illness'):

**Margaret:** The essence of me still exists but it doesn't work as well as it used to.

Here, there was a sense that the pre-illness identity was being constrained by an enforced, unwanted identity.

**Jim:** It's not as if you're going off and doing what you want to do going on holidays, going and playing golf well you're not, you're trapped in your own little world.

Consequently, as pre-illness attributes were experienced as increasingly inaccessible, feelings of failure, loss of confidence and frustration began to emerge ('negative consequences of self-illness conflict').

**Lucy:** I well, I don't know, I feel like a failure really. I think the fact that I don't have my job anymore um, I'm not as active as I used to be, not socially I don't really have a social life, I don't do any of the things I used to do.

**Rose:** And if I'm talking I am so slow at you know retrieving the words so that's frustrating you know, if only I could achieve better there, you know I'd be happier with that.

Here, in describing self-illness conflicts it was noted that individuals seldom engaged in criticism of the pre-illness self/existence, invariably describing it in a positive light, emphasising distress associated with its perceived inaccessibility.

### 3.5: Making Sense of the Illness Experience

However, as the degree of conflict and associated distress was observed as varying/shifting across and within interviews, it became necessary to consider how the varying ways in which individuals make sense of illness, mediated these conflicts.

#### 3.5.1: Questioning Illness Validity

Primarily, it was observed that as individuals attempt to make sense of continuously shifting symptoms and uncertain illness trajectories, a process of self doubt and questioning of the
validity of the illness experience began to emerge. This typically resulted in individuals wrestling with dilemmas such as whether CFS was ‘real’ or ‘in the mind’:

**Samantha:** ...which I suppose no-one ever really knows the answer to and I suppose it depends from one person to the next um and is it all in my head? [Talking about the possibility of recovery].

**Peter:** I wanted to prove now that it wasn’t my head you know, I desperately didn’t want it to be my head.

Alongside explicit questioning of illness causes, constructions of validity arose under other conditions, typically following periods of improvement/recovery, whereby symptom intensity and objective markers of ‘physical illness’ were experienced as lessened.

**Samantha:** Because I don’t always feel like it and I suppose when I felt like it more and it was more constant, then I felt the physical kind of symptoms more [in response to – “what makes you think it’s all in your head?”]

In doing so, some people described re-considering their sense of self following symptomatic improvements, questioning whether they were somehow dishonest or ‘mad’:

**Rose:** It’s a mixture of good and bad really there is also a sort of feeling mixed in with it that I’m a charlatan and that I’ve been conning people [talking about her experience of better days].

**Emily:** It gets to the point that you don’t know whether you are actually ill or not. You think maybe I’m just going mad.

### 3.5.2: Questioning Agency
Alongside assessments of validity, individuals frequently questioned their sense of ‘agency’ or capacity to enact change/exert control over the lived existence. For some, these incidences were accompanied by self-blame and feelings of guilt:

**Emily:** It doesn’t really have a huge impact because you know that you’re just feeling so unwell you don’t have a choice and therefore you don’t feel particularly guilty. [Discussing dilemmas around social contact].
Here, periods of worsening symptoms were associated with increased illness validity and a removal of choice/responsibility, whereas symptomatic improvements individuals led individuals to question their agency to a greater extent.

**Rose:** And um I was blaming myself a lot that it was my fault um that you know if I just pulled myself together I’d have loads of energy, I can do whatever I like.

As such, improving symptoms elicited dilemmas around whether illness experience and thus recovery were within personal control and thus, the extent to which inability to engage in activity was somehow chosen:

**Margaret:** Am I avoiding it because it means re-engaging or am I avoiding it because I just can’t do anymore than I am currently doing? [referring to capacity to engage in academic work].

3.5.2.1: Feeling disbelieved/misunderstood

The above constructions were typically influenced by interactions with others who were perceived as questioning the validity of illness and perceiving recovery as within personal control:

**Lucy:** There is definitely stigma attached to it, that you’re um a weak person or you’re lazy or you, you’re not trying hard enough, you know that sort of thing.

This emerged from a wider category of ‘feeling misunderstood’, often associated with experiences of feeling pressurised to undertake activity in order to meet other people’s demands:

**Margaret:** Well he says “you will push yourself if you really want to do it” but what he doesn’t understand is that there’s a consequent cost [speaking about her husband].

**Lucy:** ...you should go out and exercise and you should go to the gym, you know that sort of thing which is quite heart breaking [speaking of others responses].

For some perceptions of disbelief were linked to perceived discrepancies in levels of activity (‘good days masking illness’), in that undertaking social contact necessitated periods of improvement, limiting others’ awareness of the full illness experience:

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Lucy: ...and then maybe one day you can be a little bit better, you know that doesn't make sense to them, it doesn't make sense that you're tired, they just think well you're tired, it's just tiredness.

Thus, the outward 'healthy' appearance was constructed as a barrier, hiding illness from others, perpetuating experiences of disbelief ('outward appearance masking underlying illness'):

Jim: You can't get it across to people, because you don't look ill you know, people come to visit they expect you to look ill um and I say to them you know if you spend some time with me, then you'd realise.

As such, the absence of 'objective' illness markers influenced individuals' constructions of how they were perceived by others:

Samantha: I think also because it's something that's not, you know I always say it's not like you've got a cast on you're leg is it and it's just [becomes tearful] you don't know if people are going to understand.

Here, some individuals came to believe that the illness experience was seen as in some way 'chosen' by others, fuelling wider dilemmas about agency:

Jim: He said 'oh I don't believe all that' and I said well, I hope you don't get it then and he said 'well I won't get it because I don't want it'.

Margaret: I get annoyed with them when they tell me I just do everything I want to, but it looks like that to them.

3.5.3: Justifying Illness

A natural consequence of these dilemmas was that individuals began to justify the illness experience (sometimes overtly within conversation) as valid and thus beyond personal control:

Lucy: I didn't ask for this. It's not something I want at all, I can think of so many other things I'd rather have than have this...you know I'd rather have every bone in my body broken and just take my chances than just end up being like this.
On other occasions, justification arose through a process of pathologising symptoms as ‘abnormal’ by using other ‘healthy’ individuals (or the pre-illness self) as a benchmark for comparison, thus emphasising the discrepancy between ‘normal and abnormal’ and constructing the illness experience as ‘real’ and ‘different’ from everyday ailments:

Emily: *And then you go and try to do something and you realise no, I really can’t, or you see somebody else doing something that there’s no way that you could do it and it sort of brings, gives you a reality check.*

3.6: Strategies for Negotiating Self-Illness Conflicts: Distancing versus Integration

While justification is a natural consequence of dilemmas surrounding agency/validity, constructing illness in this way poses implications for attempts to reconcile self-illness conflicts. Specifically, participants described many ways of managing CFS. Here the ‘strategies’ adopted were sometimes mentioned explicitly within the context of ‘getting by’, whilst at other times emerging more implicitly through different patterns of relating to illness; responses seemingly reflecting a continuum regarding the extent to which illness was integrated within, the lived experience and thus constructions of the self.

3.6.1: Distancing

One means of negotiating self-illness conflicts was through a process of distancing or separating the self from the illness experience.

3.6.1.1: Resisting self-illness changes

Here, in distancing the self from illness, many individuals (especially those experiencing frustration in response to self-illness conflicts), found themselves resisting self-illness changes, expressing continued identification with pre-illness values, typically through ongoing attempts to perform ‘as if’ the pre-illness self; these efforts continuing even when CFS was well established:

Rose: *Trying to behave like you’re the same as everybody else and then every so often something crops up and you have to say oh actually I can’t do that.*

In doing so some individuals described pushing themselves and fighting against decreased activity levels ‘exceeding limits’ in the pursuit of increased activity:
Margaret: And one of the interesting things I've learnt and actually this is typical of me, if I gave in to my tiredness all the time I'd be asleep half of my life, I fight it and I realise that I've got into the habit of fighting it which is not good, you really need to not fight it, but because, if you don't fight it then you don't have a life at all.

Here, the tendency to strive towards increased activity was reflected by a tendency to use capabilities of the pre-illness self or other 'healthy individuals' as a benchmark for judging progress, thus resisting self-illness change through continuously undermining activities not consistent with the pre-illness self ('undermining current progress'):

Margaret: But I mean, I've, I've had lots of ideas you know my brain hasn't stopped having ideas, it's, perhaps they are not as good as the ideas I used to have.

Rose: It didn't seem appropriate that the toast should include my successfully locating and ordering a pepper mill on the internet, which was my achievement for the day!

For others, resisting self-illness change emerged more explicitly in association with a need to evade acknowledgement of those changes and associated losses; one individual describing a conscious need to fight acceptance of self-illness conflicts pertaining to independence:

Lucy: I think also, deep down and I think it was just like admitting defeat in a way for me, it was just like admitting defeat, so I did stupid things like um I used my credit card and maxed it out and that type of thing [talking about not wanting to accept state illness benefits].

Here, resisting self-illness change and thus avoiding 'defeat' or 'not giving up' not only perpetuated continuing identification with pre-illness values and attributes, it also confirmed illness as something unwanted and separate from the self.

Lucy: It's er it's a complete, it's a complete change really, it is a complete change, my life is completely different, it's quite staggering really, it's not you know how it was and it's not something that I want to get used to either.
3.6.1.2: Containing illness

A second more implicit way of distancing self from illness was by ‘containing illness’ from both others and the self, through a process of concealment or ‘hiding’ e.g. *keeping others unaware* by presenting a façade of wellness:

**Lucy:** So I was desperately trying to not appear to be too sick.

Conversely, for others illness was contained by not disclosing, due to anticipated negative evaluation or misunderstanding in response to disclosure:

**Rose:** Yeah ‘cos I think, yeah because people with illnesses are boring so I tend to try and conceal it when I’m out in the big wide world.

**Samantha:** I think in a way it’s because you don’t want people to perceive you any differently [speaking of reasons for non-disclosure].

Here, even within close relationships, some individuals still tried to keep others unaware, linking disclosure with forced acknowledgement of the ‘reality’ of self-illness losses and the resultant illness existence:

**Samantha:** Um, it’s almost like admitting defeat um because I’d come so, so far [Talking about disclosing to close friends].

**Separating self from illness**

For others, containment occurred through separating illness from the self by locating CFS within the body - typically following experiences and explanations provided during the process of diagnosis – through use of ‘medical’ or physiological terminology in identifying biological correlates of illness. Here, individuals constructing their illness experiences with, from their perception, a clear and non-contestable physical mechanism (Margaret and Peter), seemed to engage in fewer assessments of validity and agency, reporting lessened experiences of guilt and self-doubt.

**Margaret:** But since I’ve been proven to have Chronic Fatigue and I understand the chemical impact of it on my body I’m a little more forgiving [speaking of dilemmas surrounding agency].
Peter: But because of these tests I had up at [names location] ten years ago... I'm the luckiest one there because I've got a bit of paper that says I'm ill or I have a problem, none of the others have got a bit of paper because, they can't prove it.

A second means of separating the self from illness was through 'being controlled by the body', thus constructing symptom fluctuations as beyond individual control ('blaming illness'):

Rose: When various bits of it hurt or refuse to function properly, I don't get cross with my body, I get cross with the ME, which is an extraneous entity.

Here, at the extreme end of illness justification, Rose constructed CFS as a completely extraneous and separate entity; this understanding seemingly providing a mechanism for mediating feelings of distress associated with self-illness conflicts and associated dilemmas of validity/agency.

3.6.1.4: Controlling Illness

Similarly, some individuals described struggling to resist self-illness changes, controlling emotional aspects of the illness experience by 'blocking off'/resisting feelings of emotional distress associated with self-illness conflicts ('controlling emotions associated with the illness experience') and thus evading acknowledgement of illness related losses:

Peter: I don't like watching films, I watch um you know the nature things, anything that's got emotion in it I just can't handle um.

Lucy: I'd rather try to take my mind off of the things and like not to talk about my thoughts and feelings all the time.

For others, the physical aspects of illness were controlled through use of external agents such as food, medication and specialist treatments ('controlling symptoms using external agents'):

Samantha: That's another thing that I can control and if, all it needs is an injection once a month then that's fine [laughs] so I suppose you know I'm very aware of that as well.[Speaking about injections of B Vitamins]
Thus, where attempts to make sense of illness necessitated a construction of illness as an uncontrollable bodily/extraneous entity, CFS became constructed as something to be resisted against and overcome; here the use of containment/control possibly serving to emphasise the illness experience as outside of personal control.

3.6.2: Integration

Of course not all the negotiation strategies observed could be constructed within a framework of separating or distancing illness from the self. Conversely, some individuals came to both tolerate and embrace the illness experience within their lived existence and sense of self.

3.6.2.1: Adapting activity to facilitate engagement with pre-illness roles/values

One process of integrating illness within the lived existence was through adapting activities associated with the pre-illness lifestyle in ways more compatible with illness, thus mediating the degree of self-illness conflict. For some, these attempts appeared linked to the legitimisation of the illness experience and reduced tendencies to question illness validity and agency. As such, Margaret and Peter (who both had a clear biological explanations for their experiences) described accommodating illness: Margaret through channelling her love of academia and initiating change in professional systems into alternative roles (teaching languages to friends and adapting local craft fair initiatives); whilst Peter accommodated his love of reading and literature through filling his days listening to audio plays and undertaking voluntary work.

**Margaret:** I love to teach. I absolutely love it um, that hasn’t changed um it’s really funny even though I’m not well and I can’t do, teach what I used to teach I find myself teaching friends of mine who are foreign how to speak English properly.

Similarly, although Jim acknowledged the role of mental attitude in facilitating recovery, this was not equated with assessments that the cause of illness was internal or ‘in his mind’. As such, he was able to mediate the degree of conflict between the illness existence and his pre-illness role as a ‘contributer’, through adapting ways in which he was able to contribute around the home with his wife and children:

**Jim:** Yeah it’s about having to adapt do things slightly different um, you know I’m going shopping with [names partner] I always go food shopping with [names partner] and she pushes the trolley ’cos it tires me out.
Thus Jim, Peter and Margaret were observed as finding outlets for important values associated with their pre-illness self, which would be undertaken despite illness.

3.6.2.2: Building new roles and interests more compatible with illness

For others, self-illness conflict was mediated through the development of new roles and interests more compatible with illness symptomatology. This could comprise taking up new hobbies (e.g. Jim took up bird watching) or occupational roles. Here, after becoming unwell Samantha shifted into a role which she deemed more flexible (because of holiday times and working hours), thus mediating her experience of self-illness conflict through continuing identification with her pre-illness ‘hard working’ self. Similarly, Margaret developed an interest in craft, whilst Rose adopted the role of ‘listener’ within the family:

Margaret: If you wake up at 2 in the morning because you fell asleep at 10 and you can’t go back to sleep you’ve got something that you can do that doesn’t interfere with anybody... It fits in brilliantly with someone who has Chronic Fatigue.

Rose: I think I’ve fulfilled a function in being there for people to talk to you know when they’ve got difficulties I feel I serve a function for our two mothers and our two daughters and I would with my husband but he’s quite a closed person so he doesn’t talk about his problems um but I feel that is a useful function I have in my life that I can’t do lots of physical stuff but I can listen and sympathise and so on.

Interestingly for Rose a further shift in identity was associated with her developmental stage:

Rose: I felt such an odd ball and that really added to this sense of not having an identity anymore because I’d given up work, but now I feel I’m sort of perhaps working my way into perhaps gaining an identity again as a retired woman, you know perhaps I’m allowed to be that.

Thus, the advent of retirement provided a match between the illness existence and her developmental stage, legitimising an identity where illness related changes were embraced by the wider society.

3.6.2.3: Processes of integration

Integrating illness within the lived experience was typically associated with several other processes whereby standards and expectations were lowered to facilitate engagement with
valued activities ('lowering standards'), typically through balancing activities and rest ('pacing' and planning):

**Margaret:** I plan the activities and I try and fit the others stuff in around it.

**Jim:** I might have a go at doing a bit of polishing now and again but she tells me not to bother you know but I know having her around makes it so much easier for me. [Talking about contributing through supporting wife].

Here, engagement with such processes was dependent upon the capacity to acknowledge, legitimise and value reduced levels of activity, this facilitating a lessened pre-occupation with attainment of pre-illness standards ('identifying positive self-illness changes'):

**Margaret:** So I'm trying. I'm doing things that are more fun [referring to new interests post-illness onset].

**Samantha:** ...and I didn't want to get stuck in that rut so I suppose, in a way I saw the light early, early enough to do something about it. [Referring to shift from corporate to public sector work].

Here some individuals were able to identify themselves as having learnt important and valued lessons through the illness experience, typically becoming more appreciative, understanding and caring towards others as a result:

**Emily:** Because you only have a certain amount of energy which means that you get really good at tuning into people quickly because you know you've only got a very limited time with them you've got to quickly get on their wavelength in order to get some really good conversation going.

However, it was noted that very few individuals spoke of such changes without prompting, raising questions as to what extent they reflected meaningful self-constructions.

### 3.6.3: Integration versus Distancing: A Shifting Continuum

Of course it would be a mistake to imply that integration and associated processes formed some categorical either/or construct. Conversely, in parallel to experiences of shifting symptoms and dilemmas of agency/validity, such processes fluctuated over time. For
example, until recently, Samantha appeared to be accommodating illness within her existence to such an extent that she deemed herself as recovered. As such, her experience of a recent relapse following improvement re-awakened issues of validity and agency, necessitating attempts to contain illness from others, in order to evade recognition of self-illness losses and maintain others’ perceptions of her as ‘hardworking’:

Samantha: But the school you know, the people I actually worked with didn’t know so I suppose communication is probably one of my downsides um, I think in a way it’s because you don’t want people to perceive you any differently.

Furthermore, distancing and integration may occur co-morbidly as if battling against one another. As such, whilst Margaret showed evidence of integrating and accommodating illness within her life, she continued to use pre-illness standards as a benchmark, thus finding herself caught between embracing and undermining these efforts:

Margaret: But I mean, I’ve, I’ve had lots of ideas you know my brain hasn’t stopped having ideas, it’s, perhaps they are not as good as the ideas I used to have.

Indeed, when these ‘negotiation’ efforts are considered alongside the backdrop of symptom uncertainty, it becomes easy to understand why individuals struggle to accept self-illness changes:

Lucy: You might have say two awful weeks, you might have a good day, you might not be able to help yourself, it’s just like dangling a carrot really.

Rose: It’s just so depressing when you find that your back to the way you were, it’s like Cinderella has been to the ball and is back in her rags again.

Here, in a world where illness validity and agency are continually questioned by the self and others, constructions of illness as distanced or separated from the self allow individuals to hide illness away, evading further rejection and disbelief whilst also reducing distress associated with acknowledgement of self-illness losses. As such the ‘self’ and its relationship with illness are rendered fractured and separated across different settings, attempts to achieve any integration/accommodation being hindered by sporadic re-engagement with the pre-illness self on better days.
3.7: Willingness to Contemplate the Future

The ways in which individuals make sense of illness and subsequently negotiate self-illness changes have implications for the process of thinking about the future; this being something many found difficult, questions about the future typically being greeted with silence, avoidance (such as ‘I don’t want to think about it’) or confusion. Thus, in trying to explore constructions of the future underlying these responses, the ease with which individuals spoke about the future appeared closely linked to assessments of their capacity to enact it.

3.7.1: Assessing the Capacity to Enact the Desired Future: Degree of Constraint Posed by Illness

Here, when assessing the capacity to enact the desired future the issue of conflict again arose, this time regarding the constraining role of illness on the capacity to move forward, most participants at some stage, experiencing conflict between the current illness existence and future plans:

Margaret: Well it fits crap [referring to the fit between current/future existence] doesn’t it [laughs] it absolutely fits crap. I mean, I feel like, you know, I have all these great ideas and I, I can’t put them into execution.

For some, this conflict was related to shifting developmental stage issues (‘influence of developmental stage’). Thus Margaret questioned whether she was now ‘too old’ to return to her academic career, whilst Rose considered the prospect of others’ increased dependence upon her as she entered a phase in her life where she felt expected to care for both her grandchildren, husband and elderly parents. Conversely, Lucy (in her late twenties) questioned whether she could meet a partner and have children, whilst Emily, a young woman growing up with CFS, recounted concerns surrounding developmental tasks around gaining independence:

Rose: Because I shall feel like I should be looking after the children, because I’ve got all the time in the world, but I’m not capable of doing it.

Emily: I can’t go and assume that I’ll be independent, any plans that I make for the future I have to make sure that I’m near my parents.
3.7.2: Presence/Absence of Illness in the Future

The degree of conflict brought about by these assessments reflected the emphasis on goals of the pre-illness self within the desired future, which were thus deemed incompatible with illness 'seeing future plans as dependent upon recovery'. Thus patterns of negotiating the original and ongoing identity challenge of CFS became influential within constructions of the future, many individuals again fracturing illness from their constructions of the future, regarding illness as temporary. As such, there was a sense that future goals and life plans essentially remained largely unchanged, with activity, independence and employment remaining central:

**Emily:** Well the way that I hope the future would go would be that I'd get back to University in a year or two's time, do so much more stuff that anybody, that any Uni student would be doing, safely far away from all the bad stuff that's gone on.

**Lucy:** Start to go back to work, I'd like to go back to work and start part-time and that would be the first thing I'd like to do.

Conversely where the illness experience was deemed more satisfactory and thus tolerable, by virtue of increased accommodation, thoughts of the future appeared less dominated by illness related conflicts. Here, for Peter, the current existence was experienced as both unavoidable and satisfactory, thus remaining ongoing in the future. Similarly, Jim's ability to integrate illness within his current existence was also associated with an ability to build plans consistent with illness in the future:

**Jim:** Yeah we were even talking about fostering you know being foster parents, so we have actually looked at that.

**Interviewer:** Is that something you feel you could do kind of at the moment?

**Jim:** Well if [partner] was here as the main carer and I was just like the back up then yeah we probably could do it as a pair. It won't be easy we know that, but that's part of the enjoyment of it, that's something that's hopefully in the pipeline.

3.7.3: Considering Alternative Futures

Whilst respondents generally fell into categories of integrating illness within the future or seeking an unchanged future, this again was not a categorical process. Conversely, individuals constructed their futures as a mix of intense hopes and fears, frequently swinging
between conceptualisations of a future where illness was either present or absent. For most this emerged as conflicting plans for the future with any attempts towards integration, occurring alongside plans to return to the pre-illness way of life (Jim, Margaret). Some were quite explicit about this sense of being caught between two polarised futures where illness persisted or diminished:

Emily: What I fear my future will be like might be, that I'm stuck just being on and off ill all the time and never really reaching my potential. [this contrasts with Emily's hopes discussed above].

Here, just as attempts to negotiate challenges to identity were influenced by uncertainty, periods of recovery placed the unchanged future back within close grasp, whilst periods of relapse were associated with feelings of hopelessness about the future ('future plans influenced by shifting symptoms'):

Lucy: When I have a good day, I still like to think about the things that I would like to do, whether it's a job or an interest or you know.

Lucy: I don't want to get into a situation where I just feel like I've given up and I just think well, it's not ever happening, I'm never going to be able to have kids or I'm never going to have a relationship.

Thus, in the same way as distancing/separating illness from the self allowed continued identification with the pre-illness self (discussed during negotiating strategies) through evading recognition of self-illness losses, similar processes were influential in constructing visions of the future.

3.7.3.1: Being stationary

As a consequence of being caught between alternative futures, individuals can become immobilised in the face of uncertainty. Here, where desired futures were dependent upon recovery, many individuals described a sense of being stationary and not progressing, their experiences being constructed through 'waiting and hoping for recovery':

Rose: But then if you asked me specifically do I dwell on the future I think I'm a bit of a Scarlet O'Hara really in that I, I just prefer to think oh well things might be different by then and then I dismiss it that way I think "oh well the ME will be gone tomorrow".
Here, just as ‘not giving up’ was important in negotiating self-illness conflicts, waiting for recovery was constructed as a means of coping, maintaining hope in the face of an otherwise bleak future, beyond personal control. As such, some individuals (notably, Emily, Rose and Lucy, where agency/validity conflicts and distancing strategies were more prevalent) described an ongoing battle to maintain hope, through remaining focussed on recovery and an unchanged future.

**Emily:** *I think you have to spend a lot of mental energy keeping the side that you don’t want to win in check and concentrate on the hope side of the battle.*

For others, being stationary was linked to the impact of continual experiences of uncertainty in hindering the capacity to formulate and enact longer-term definitive plans, individuals subsequently experiencing themselves as ‘taking one day at a time’ through being task as opposed to, future focussed:

**Margaret:** *I don’t think gosh by two years time I must be doing this, you think I have these jobs to do, I’m going to try and do them as well as I possibly can and as quickly as I possibly can.*

Subsequently, the future comes to encompass brief windows of time from minutes, to days, to weeks/months; these being more tolerable than continual uncertainty/ambiguity surrounding future hopes:

**Rose:** *I have to use so much energy on the basic stuff that there’s not a lot of energy left over for other things that might give me a sense of achievement.*

Here notions of self-actualisation and fulfilment are put on hold as individuals become rooted in the present, targeting their energies towards the more achievable tasks necessary for day to day life.

### 3.8: Linkages between Categories

Consistent with the shifting and fluctuating illness biographies described, the above analysis highlights the fluid, continually shifting impact of CFS upon constructions of identity and the future.
Here experiences of uncertainty call into question the activity-based construction of the self generating a shifting sense of identity; the degree of self-illness conflict experienced, reflecting the extent to which illness is constructed as hindering the capacity to engage with the pre-illness self. The ways in which individuals attempt to make sense of the illness experience, then exerts an influence on the negotiation of this conflict. Here, explanations received during diagnosis, the degree of shifting symptoms experienced and social experiences of misunderstanding/disbelief combine to elicit questions regarding the validity of illness, which in turn automatically elicit concerns about the meaning of illness persistence and the capacity to enact change/exert control over recovery. This results in a need to justify the illness experience as unwanted, through distancing illness from the self by resisting, containing and controlling self-illness changes. Consequently, the degree of integration between the self and illness comes to influence constructions of the future, with distancing strategies giving rise to a future focussed on recovery and thus the experience of being stationary whilst awaiting symptomatic improvements. Conversely, where self-illness conflict has been mediated in some way, illness can become integrated within the lived existence and thus the self. Here it becomes possible to entertain thoughts of the illness experience as ongoing within the future, as well as the here and now.

For most individuals, however, just as attempts to ‘get by’ and negotiate illness are influenced by shifting levels of distancing and integration, the process of thinking about the future is similarly dominated by an uncomfortable mix of hopes and fears, these reflecting waxing and waning symptomatic experiences and associated dilemmas surrounding validity/agency. Only when individuals can begin to integrate illness within the self, through accommodating or developing new roles/interests more compatible with illness, can these conflicts begin to be addressed. However, even where integration does occur, ongoing debates over prognosis and periods of shifting symptoms pose a continual challenge to the acceptance of self-illness changes, both currently and within conceptualisations of the future; periods of improvement raising questions about the extent to which recovery is both possible and within personal control. Thus integration of illness within the lived existence and future plans becomes synonymous with loss of hope, giving up and perhaps at a more unspoken level somehow suggests that the illness experience is somehow chosen or wanted. Consequently, illness remains constructed as distant and separate from both the lived existence, self and future, perpetuating feelings of immobility as individuals remain focussed on the here and now, hoping and waiting to re-capture the pre-illness existence.
Figure 1: Summary of the Emerging Theory.

Becoming Unwell
- Experiencing uncertainty
- Experiencing changed relationships
- Experiencing multiple and varied symptoms

CFS as a Challenge to Identity
- Conflict: between current existence and pre-illness self
- Confusion
- Loss

Making Sense of the Illness Experience
- Questioning validity
- Questioning agency

Negotiating Responses
- Distancing (self-illness changes and illness itself) vs integration

Willingness to Contemplate the Future
- (Blocking versus Engagement)
  - Assessing capacity to enact the desired future (considering alternative futures)
  - Degree of constraint posed by illness
  - Presence/absence of illness within the future (temporary versus integration)
4. DISCUSSION

The following section considers the current findings within the context of wider theoretical and research evidence bases, before presenting recommendations for further research, tentative implications for clinical practice and a critique of the current study, all of which have been informed, in part by the researcher’s reflections on the research process.

4.1: Responding to the Initial Research Questions: Finding a Place within Extant Theory

To re-cap, the study aimed to explore ways in which individuals living with CFS experienced and thought about themselves, their futures and who they may become, specifically focussing on the explication of processes informing the development and maintenance of such constructions.

4.1.1: CFS as a Challenge to Identity

In considering these aims, this work has highlighted the closely intertwined relationship between identity and illness, emphasising the challenge presented by CFS to the identities of those living with the condition.

Here, consistent with other theoretical notions of self, where the body is regarded as the embodiment of who we are (Ponty, 1962), the development of CFS led individuals to question their sense of identity, strengthening theoretical understandings of the self as a continuously shifting entity (Charmaz, 1987). Furthermore, the current study relates the degree of identity challenge experienced, with conflicts between CFS and the activity-based construction of the pre-illness self (consistent with Aspring, 2001), multiple and fluctuating symptoms disrupting engagement with previously valued activities. These findings build upon experiences of self-loss following experiences of passivity (Aspring, 2001) and immobility in CFS (Clarke & James, 2003), also echoing Hellstrom’s (2001) concept of entrapment among individuals with chronic pain. As such, individuals with CFS came to experience themselves as constrained by illness. Here, the development of CFS serving to mask/hinder the enactment of the activity-based self, the significance of which possibly reflecting emphasis upon independence and achievement within the study’s broader westernised/individualistic cultural context.
4.1.2: Making Sense of Illness

In a contrast to other literature the current findings emphasise the role of the illness context in negotiating self-illness changes; wider contextual experiences of symptomatic uncertainty (with regards to shifting symptoms, cause, onset and prognosis of CFS) being emphasised to a greater degree than within previous work (Clarke and James, 2003). Consequently, the experience of CFS was observed as being consistent with Charmaz’s notion of an intrusive illness, dominated by ‘good days’ and ‘bad days’ alongside changing interpersonal relationships characterised by loss and feelings of being misunderstood/disbelieved (consistent with Clarke and James, 2003). However, the current study moves beyond simply describing such experiences, emphasising their role in informing attempts to negotiate/understand the illness experience. Here, the combination of ongoing experiences of uncertainty with regards to symptom fluctuations, cause and prognosis were observed as important, as were wider experiences of being disbelieved by others. In particular, these experiences influenced the extent to which individuals questioned both the validity of CFS, whilst also informing their perceptions of the level of choice within/responsibility for the lived experience. Specifically, the term agency was used to refer to constructions regarding the capacity to make changes within/exert control over the illness and recovery process31.

4.1.3: Negotiation of Self-Illness Changes

As individuals attempt to negotiate self-illness changes, these ways of making sense of illness were observed as influencing emerging relationships between the self and illness. Primarily, experiences of uncertainty and assessments of spurious validity/agency (by self and others) appeared to necessitate justifications of the illness experience as ‘real’, unwanted and thus beyond personal control. For some, this was undertaken through overt conversational pronouncements, explicitly stating their perception of CFS as unwanted, whilst others adopted a distanced/separate relationship with an illness located within the body and thus justified as valid (by virtue of physiological correlates) and beyond control. Here, by containing illness, further recognition of self-illness losses and confirmation of negative self-perceptions were evaded. This seemed to echo Charmaz’s observations of the way in which non-disclosure became important in avoiding acknowledgement of illness related losses within chronic illness more broadly (Charmaz, 1991).

Similarly, other individuals actively resisted self-illness changes and losses through ongoing endeavours to re-capture pre-illness levels of activity, consistent with Hellstrom’s (2001)...

31 Throughout the discussion the term ‘agency’ will be used in this regard to refer to individual constructions of the level of choice/responsibility within the illness experience. Specifically, the term agency refers to individuals’ constructions of their capacity to exert control over, and make changes within, the illness and recovery process.
notion of maintaining consistency with the past self. However, whilst such stances temper distress associated with dilemmas of validity/agency, they appeared to perpetuate divisions between self and illness, the former engaging in a battle to overcome the latter through containing, controlling and resisting self-illness changes. Here, the construction of the body as separate from the self and consequent battle against illness were akin to that documented within Hellstrom’s notion of a ‘distanced, foreign body’ not fully integrated with the self, alongside wider modern ‘militaristic’ medicinal metaphors within which illness is treated as a foreign enemy to be vigilantly avoided, contained and eradicated (consistent with Duff, 1993 and Clarke, 2000).

By contrast, some individuals were observed as integrating illness, accommodating pre-illness activities through processes such as pacing, lowered standards (consistent with Charmaz, 1991), or developing new roles/interests more compatible with illness, as observed by Aspring (2001). Here, the process of accommodation also reflected Charmaz’s notions of preferred identities after illness, these reflecting dominant discourses to the extent that ‘doing’ continues to be accomplished in spite of illness (1987). However, in contrast with Aspring’s observations of new identities among individuals with CFS and Clarke and James’s findings pertaining to an emergent ‘radicalised’ self, whilst some individuals identified positive self-illness changes (usually relating to increased compassion or shifting life values), for many such observations did not emerge unprompted, raising questions as to their importance within underlying self constructs.

Furthermore, with regards to the process of integration, the current results conflict with traditional categorical or linear models of adjustment such as that proposed by Fennell (1993) within the Fennell Phase Inventory32. Here, Fennell’s four phase model of adjustment within CFS begins with an initial crises phase, where traumatic aspects of a new illness are experienced. In Phase 2, continuing chaos and dissembling are experienced pending later stabilization of the individual’s symptoms. Subsequently, in Phase 3, individuals are argued to move into ‘resolution’ mode as illness chronicity/ambiguity are accepted, providing meaning within the illness experience. Finally, integration can be achieved as individuals integrate pre- and post-illness self-concepts. Here, whilst experiences akin to each of these stages were observed within the current study (as would, no doubt, be highlighted through a single FPI administration), the process of integration was not observed as being linear, seeming to remain continuously fluid across the illness experience, in response to the shifting

32 A questionnaire-based tool used to assess adjustment within CFS.

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influence of contextual experiences on influencing assessments of validity/agency and subsequent relationships between self and illness.

As such, the current findings are supportive of Aspring’s work identifying the presence of partially integrated and sometimes co-occurring discrepant identities in response to the illness experience (2001), reflecting the extent of biographical disruptions. Yet, the current work moves beyond these findings to suggest that the level of biographical disruptions experienced may reflect the impact of continual and ongoing experiences of shifting symptoms on both assessments of validity/agency (necessitating a distancing of self from illness) and continuing identity with pre-illness values. As such, consistent with Hellstrom (2001) and Narius (1991), the study supports understandings of adjustment as more complex than merely “losing” or “gaining” aspects of the self in a linear fashion. Consequently, there is a need to acknowledge the role of wider social/contextual influences, in influencing the efforts made by individuals to reconcile changes associated with the illness condition.

4.1.4: Contemplating the Future
Consistent with temporal understandings of the self, the self-illness challenges identified within the current study extended towards contemplation of the future. Such findings are consistent with theoretical understandings of the self proposed by Cantor et al (1986) who stated that the very act of thinking about the future is inextricably linked with issues of identity, through consideration of representations of how we might go on to look and feel. Similarly, Narius (1991) suggests that constructions of the self in the past come to influence possible future circumstances, providing an evaluative context for the current existence. Consistent with this, within this study, the presence/absence of illness in the future reflected ongoing efforts to distance/integrate illness within the lived existence. As such, for many, the future represented a continuation of the pre-illness self (consistent with Charmaz’s notion of an ‘unchanged’ future reflecting attempts to re-capture the past), which thus became a benchmark for evaluating progress within the current existence. Interestingly, here the pre-illness self was often constructed in a positive way, again echoing Charmaz’s notion of reconstructed past, shining bright with happiness, fullness and vibrancy as a means of rejecting identification with the present (1990).

Whilst for some, illness came to be accommodated within conceptualisations of the future, through the integration of lessons learnt through illness within future plans (consistent with Clarke and James, 2003), for many the integration of illness within the future was not a categorical or linear process. As such, whilst Charmaz (1990) highlighted a range of stances

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in relation to the future, in association with changes in the relationship with time associated with shifting experiences of illness (e.g. intrusive, interruption), the current study identified co-morbid, fluid and alternating constructions of the future. Here again, the continually shifting nature of such constructions seemed to relate to wider contextual experiences of uncertainty alongside assessments of validity and agency. Thus, periods of improvement seemed to result in individuals questioning the validity of CFS and their capacity to exert control over the illness experience. Subsequently, maintaining consistency with the pre-illness self and pre-illness plans for the future became important; this serving to both maintain hope (of recovery), whilst also justifying the illness as unwanted through ensuring that individuals were not seen to be ‘giving up’ (by themselves or others). Here, in contrast with other literature where perceptions of increased social support were linked to more ‘positive’ attitudes towards the future (Hellstrom, 2001), anticipated dependency (when experienced alongside uncertainty and spurious validity/agency) typically gave rise to a sense that the future was beyond control and thus hopeless. As such, similarly to Charmaz’s (1990) findings, many individuals displayed shifting relationships with time, becoming rooted in the present through taking one day at a time. However, whereas Charmaz observed that such processes were linked to an acknowledgement of and attempts to cope with, illness losses, the current work suggests that such efforts may be driven by attempts to evade recognition of self-illness losses and associated emotional distress.

Thus, to summarise, it is clear that the experience of CFS poses significant implications for the ways in which individuals think about themselves and in turn the future. However, whilst many of these experiences are comparable to those described across individuals with chronic illness more broadly, in contrast to pre-existing literature, the contextual experiences and social processes surrounding the experience of living with CFS render the process of reconciling self-illness changes, and their impact upon expectations for the future, a continuously shifting process characterised by conflicting constructions of the illness experience.

4.2: Potential Implications

4.2.1: Clinical Implications
The above findings lead on to a consideration of the potential implications of the study’s findings across both clinical and research settings. Specifically, the current work suggests that issues of identity and expectations for the future influence the process of adjustment within CFS. Here, if we consider this study alongside Morley’s (2005) observed associations...
between reduced self-pain enmeshment – i.e. where attainment of the hoped-for self was not dependent on the absence of pain, being achievable even with ongoing pain – and increased adjustment to chronic pain, addressing such issues within a therapeutic context may have significant implications for reducing emotional distress and increasing adjustment.

As such, the current findings pose implications for traditional Cognitive Behavioural Therapeutic (CBT) treatments for CFS, which remain the dominant approach recommended within Department of Health guidelines (DoH, 2001). Here, the focus of treatment typically aims to facilitate a cognitive reappraisal and control of, thoughts/feelings associated with physical symptoms and activity avoidance (Chalder, 1995). Consequently, such treatments, like many other medicinal approaches, position patients as active and responsible for their circumstances (Kugelmann, 1997). Thus when considered alongside the current findings it is possible that such treatments may both overlook central conflicts around identity/adjustment, whilst also perpetuating assumptions that the illness experience is somehow within personal control, inflating dilemmas around agency and validity. This may in part explain elevated drop out rates for CBT treatments in CFS (Akagi et al, 2001), psychological treatments serving to activate dilemmas of agency/validity, by virtue of being eliciting beliefs pertaining to psychological causes for the illness experience.

As such, it is possible that service provision for CFS may benefit from a similar paradigm shift to that recently occurring within chronic pain populations. Here ‘third wave’ treatments developed from the Acceptance and Commitment Based Therapy (‘ACT’) model focus on the promotion of non-reactive acceptance of distressful thoughts and experiences, thus facilitating broad, flexible and effective repertoires, as opposed to eliminative/controlling approaches. Subsequently, treatments aim to develop a propensity to ‘face’ and tolerate uncomfortable thoughts/feelings (McCracken et al, 2004), allowing resources to be targeted toward finding realistic ways of ‘doing’ that facilitate the achievement of personally important ‘being’ goals (e.g. to be successful/happy, Morley, 2005). Here, the counterproductive nature of attempts to control/reduce symptoms are emphasised and relaxation exercises utilised to improve functioning through facilitating awareness/acceptance of physical sensations; where acceptance involves experiencing some suffering to enable a healthy course of action, rather than resignation to all suffering (McCracken et al, 2004). Consistent with this, emerging research has identified the benefit of mindfulness-based meditation approaches (promoting non-reactive acceptance through meditation) in improving both subjective ratings of fatigue and quality of life within individuals with CFS (Surawy et al, 2005).

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4.2.3: Research Implications

However, before such implications are enacted it is necessary to broaden the evidence base concerning identity and contemplation of the future within CFS. Primarily, given the way in which the current study has furthered pre-existing theory, it is important to explore the extent to which such experiences and the associated emerging theory are relevant among other groups of participants with CFS. Here, given the limited number of participants within the current study (discussed below) it may be useful to include a wider number of participants or even extend interviews across multiple time points and visits, in order to emphasise the shifting nature of identity constructions within a longitudinal framework (consistent with recommendations by Aspring, 2001).

Similarly, in order to extend the current findings, it may be useful to focus more specifically on aspects of embodiment and assessments of agency/validity as separate issues, providing a more detailed account of processes and conditions informing such constructions. Furthermore, terms such as ‘acceptance’ and ‘adjustment’ have been used somewhat widely within the current study, largely from the perspective of the researcher. Indeed, as Charmaz (1991) identifies ‘acceptance’ within chronic illness has many different meanings and arises under various different conditions, which shape conceptualisations of the future as well as the present. As such, within the current study, integration and accommodation were not necessarily synonymous with ‘acceptance’ of illness within future plans. Consequently, in order to better understand to what we are referring when discussing acceptance within CFS, and thus what we are aiming for within treatment, further de-constructions of meanings associated with terms such as acceptance, adjustment are necessary, alongside explorations of the conditions and social processes informing their occurrence.

Furthermore, given the importance of social and relational experiences in influencing attempts to make sense of illness through exacerbating dilemmas of agency/validity, further research could attempt to identify and de-construct the attitudes and experiences of friends/family members of individuals with CFS. Here, the explication of such constructions and experiences could then be used to develop and inform relational and systemic approaches to therapeutic input and service provision, through identifying and addressing relational patterns influencing assessments of agency/validity within both the individual and those around them.

A further recommendation would emphasise consideration of the extent to which quantitative research studies can be utilised extending the work of Morley (2005) toward exploration of links between self-illness enmeshment and adjustment within CFS. Here whilst such
quantitative methodologies are not consistent with a social constructionist epistemological stance, their emphasis on ‘quantifiable’ measures of adjustment and outcome, render them important in providing the necessary ‘evidence’ to facilitate shifts within service provision and treatment modalities for CFS. However, given the sensitive nature of such research questions, there will be a need for careful adaptation so as to avoid leaving participants feeling objectified or further scrutinised.

4.3: Personal Reflexivity

The potential implications and subsequent limitations of this study (to be discussed below) are heightened through consideration of my own reflections upon the research process. Primarily, undertaking the research heightened my awareness of the highly emotive and sensitive nature of the research questions and the impact of these questions upon participants following completion of the interview. Here, the referring clinician, who also went on to offer post-interview support in the form of therapeutic input, commented that discussion of issues pertaining to a shifting sense of self and expectations for the future appeared to have uncovered some central conflicts, which individuals had previously been unable to explicate. Similarly, several participants requested that a copy of the transcript be placed on their medical file in order to draw any future therapist’s attention to some of the central dilemmas experienced in living with CFS. Consequently, although such accounts are anecdotal, they lend weight to recommendations regarding the importance of further research into these experiences, with a view to facilitating more widespread acknowledgement of such issues within the therapeutic context. Consistent with this, in line with the above implications, through exploring and addressing these issues within therapy, the referring clinician has begun to re-think service provision for CFS, with a view to providing more intensive and specialist services in the future.

In considering the emotive nature of the interviews it is also interesting to reflect upon my own reactions within the interview context. Specifically, I found that I was unable to stick rigidly to the interview schedule, such an approach feeling robotic and insensitive in the face of, at times, overwhelming emotion. Consequently, in line with Charmaz (2006), the interview schedule often became a guide for more informal conversations about the illness experience. Here it was difficult for me to remain separated from a more ‘clinical’ guiding role and as such, in analysing the interviews I remained alert for incidences where my responses could have been constructed as leading participant responses, attaching caution to
any interpretations drawn from these excerpts which subsequently prompted attempts to identify conflicting/disconfirming experiences across other interviews.

In addition, whilst I set out with what I hoped and thought was an open minded attitude towards CFS, constructing it as a condition to be managed irrespective of cause/aetiology, undertaking the study forced recognition of my own implicit assumptions and attitudes towards the condition. For the referring clinician within the current study and myself, these implicit assumptions often emerged whilst discussing the 'appropriateness' of individuals for inclusion within the study. Here, on one occasion we found ourselves debating whether a woman whose CFS had been preceded by a bout of meningitis should be included, the unsaid assumption being that this person's experiences may be somehow different or more 'valid', by virtue of their clearly identifiable biological precipitant. Similarly, at times, I found myself identifying with participants' experiences of being fatigued and reflecting upon my own experiences of feeling unwell. Consequently, just as my participants described difficulty disentangling what 'was illness' from what 'was them', I sometimes found myself questioning the boundary between 'normal' and 'pathological' symptomatic experiences and the influence of subjective interpretations and responses in defining this cut-off.

As such, the processes of supervision and discussion became imperative in forcing an acknowledgement and de-construction of these assumptions, this in turn, facilitating efforts to minimise their impact upon the research situation. It also helped me to remain open-minded when analysing the data, continuously looking for examples which did not fit with my own hunches and ideas, thus opening new and exciting leads, such as awareness of the way in which acceptance for some individuals was not a positive experience, being associated with defeat and 'giving up'. However, by acknowledging such beliefs, questions are raised as to their possible influence upon the interview process and resulting theory, consistent with a social constructionist understanding. Here it is possible that following the contested nature of CFS, issues of agency and validity may have reflected something of the dynamic between participants and an interviewer who came to signify the 'questioning' attitudes of other physical and mental health professionals. Consequently, the resultant focus on justification of the illness experience may have in-part reflected the re-enactment of longstanding and conflicting professional-patient dynamics. As a result, it is interesting to consider how the emerging results may have differed if the interviewer had experienced CFS or some other similarly contested condition, which may in turn present a fruitful line of enquiry within further research.

Contemplating the Future in CFS: A Grounded Theory Exploration of the Experience of Self and Contemplation of the Future Across Individuals with Chronic Fatigue Syndrome
4.4: Critique

In extending these reflections within a formal critique of the current study, a series of pertinent questions concerning potential limitations shall now be considered.

4.4.1: Is it Possible to Build a Theory from Such a Small Sample?
The time constraints and ethical requirements of the current study limited the number of interviews which could be undertaken33. As such, the emerging theory is based on the experiences of a comparatively small number of individuals, which may raise questions about the capacity for saturation within the data. However, consistent with the definitions of saturation proposed by Willig discussed earlier, for the purposes of the current study, saturation has been used as a function, rather than a goal (2001). Thus, it was recognised that undertaking further interviews may have resulted in the identification of an indefinite number of additional themes and new perspectives on the data (Glaser & Strauss, 1967). However, given the extensive, rich data produced, saturation was deemed to occur when, towards the end of coding, the number of new codes being added dissipated, instead giving way to confirmation of pre-existing codes and categories. Consequently, the ensuing comprehensive theory explicates the complex and varied ways in which participants constructed meaning within the given context, with an acknowledgement that other contexts (e.g. voluntary samples of individuals less affected by CFS and thus not seeking professional service input) may give rise to differing understandings34. As such, the impact of uncertainty and sense of being ‘stuck/stationary’ may reflect feelings associated with the need to seek professional support.

4.4.2: Can Theoretical Sampling Really Be Undertaken on a Small Sample?
When considering the sample size further, a second potential limitation relates to the way in which theoretical sampling principles were adopted within the study, time constraints hindering the ability to undertake more extensive amendments of the interview schedule in light of emerging hypotheses. In addition, whilst engaging in theoretical sampling, the sensitive nature of some of the ‘hunches’ identified (e.g. questions around agency/validity) rendered the inclusion of more direct questions related to such issues inappropriate, by virtue of the potential impact of the professional-patient dynamic between participants and subsequent risk of leaving participants feeling further scrutinised or disbelieved.

33 I.e. the need to recruit from only one clinic base where participant follow-up and subsequent therapeutic input could be provided.
34 By virtue of a less affected sample these results may be more in line with the findings of Aspring (2000) and Clarke & James (2003) within which positive self-illness changes were more readily acknowledged.

Contemplating the Future in CFS: A Grounded Theory Exploration of the Experience of Self and Contemplation of the Future Across Individuals with Chronic Fatigue Syndrome
Consequently, the focus was on identifying broad topic areas/prompts, to be deployed only when the relevant 'hunches' or issues were raised by participants.

Here, whilst a more directive approach may have led to more fruitful/specific enquiries, the author remains confident that the issues raised were reflective of pertinent participant concerns, thus facilitating more meaningful explorations of the contexts and circumstances under which such issues became significant. Similarly, adopting such a stance allowed the researcher to remain open to alternative hypotheses emerging from the data and alert to conditions where such 'hunches' were disconfirmed. In addition, it is worth remembering that the process of theoretical sampling extends beyond that of amending the interview schedule, also encompassing the process of asking questions of data already collected and identifying negative or disconfirming cases (Charmaz, 2006). As such, whilst explicit amendments to the interview schedule were not always undertaken, the researcher was able to ask questions of the data through the processes of constant comparison, continually seeking out the conditions under which identified processes occurred, whilst remaining alert for disconfirming experiences.

4.4.3: To What Extent Can the Findings and Subsequent Limitations be Extended Beyond the Current Sample?

When considering the small sample size further, concerns are raised regarding the ability to extend the current findings toward the wider population of individuals with CFS. However, consistent with a social constructionist approach, the current study did not seek to produce a theory representative of the CFS population as a whole, such an endeavour being rooted within more positivist assumptions regarding the acceptance of an external truth or reality shared across all individuals (Charmaz, 2006). Rather, the current study aimed to explore factors accounting for the research situation as it was within the sample under study. Consequently, whilst potential implications for clinical practice have been identified, further explorations as to the extent to which similar constructions may have been adopted by other individuals with CFS remain necessary.

4.4.4: Does the Resultant Theory Accurately Reflect the Data Collected?

When undertaking Grounded Theory within a social constructionist framework, it is acknowledged that the theory generated represents the researcher's interpretations of the data, as opposed to some testable external truth (Charmaz, 2006). As such, a potential concern is that the results may represent an extension of the researcher's own concerns and prior theoretical knowledge. Consequently, the researcher's experience of working clinically
within the field and the current requirements of ethics committees (necessitating literature reviews related to the research situation), may have limited the researcher's capacity to enter the interpretative process without prior pre-conceptions, influencing the nature of the emerging theory. However, consistent with the social constructionist stance (which regards such a 'pre-suppositionless' stance as both impractical and undesirable (Henwood & Pidgeon, 1992), rather than attempting to deny pre-existing knowledge, the researcher embraced and explicated these ideas from the outset, using them as a cue to engage negative case analysis throughout.

In addition, the credibility checks described in section 2.8 were also rigorously applied throughout the data collection/analytic process. As such, the researcher took care to document her thinking at each stage of the analytic process through use of informal memos, making explicit references to the relationships between higher-level categories, sub-categories and focussed codes within the write up and appendices. The researcher is also planning to disseminate the above findings within a focus group for individuals participating in the study. Here, participants will be invited to give feedback regarding the extent to which the emerging theory reflects their own experiences, these comments subsequently being acknowledged, in respect of multiple realities across the participant sample.

4.5: Conclusions

The current study highlights how the experience of developing and living with CFS presents a complex and unique challenge regarding the way in which individuals make sense of who they 'are' (identity). More specifically, continual experiences of uncertainty alongside the contested aetiology of CFS render the process of negotiating such challenges equally complex and fluid, this in turn having implications for the capacity of individuals to integrate and accommodate illness within both the current existence and expectations for the future. As such, in attempting to promote adjustment and improved quality of life, the current findings suggest that clinicians must attend to issues of identity and expectations for the future, these being pivotal in facilitating a stance of integration/acceptance as opposed to control of, and distancing from, the illness experience. It is, however, acknowledged that such implications are tentative, thus highlighting the need for further studies of the research situation.
REFERENCES


Contemplating the Future in CFS: A Grounded Theory Exploration of the Experience of Self and Contemplation of the Future Across Individuals with Chronic Fatigue Syndrome


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Salick, C. E., Auerbach. C.F. From devastation to integration: Adjusting to and growing from medical trauma.


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APPENDIX 1

(Information Sheets)
Contemplating the Future in CFS

You are invited to take part in this research study. Before deciding, take the time to read the following information. Part 1 tells you the purpose of this study and what will happen if you take part. Part 2 tells you about the conduct of the study.

What is the purpose of the study?
This study aims to explore the experiences of people with CFS/ME and how they think about themselves, and the future. This is important in increasing professional understanding of what it is like to live with this condition. This is important in informing ways of helping people adjust to their condition.

When will it happen?
Individuals from the clinic are being asked to participate between November 2006 and March 2007.

Do I have to take part?
NO, this is entirely up to you and if you decide to participate you are free to withhold any personal information or to withdraw (without giving a reason) at any time. Opting out of the study will not affect the quality of future care you will receive.

What would it involve?
Initially, the Chief Investigator will contact you and arrange a time to interview you either in your own home or over the telephone. Before the interview you will be asked to sign a consent form. The interview itself will ask you to talk about what it has been like to live with CFS and how you think about yourself. The interview is semi-structured. This means that although the interviewer will have some set questions, you will be free to talk openly about your experiences. You will also be asked to fill in a brief questionnaire about your background.

What are the possible advantages?
Taking part in research interviews can offer you a chance to: be the expert; choose what to tell and how to tell it and share significant experiences with the interviewer, teaching them how to understand your own experiences. It also gives you a chance to reflect upon what it has been like to live with CFS and influence professional understandings of this experience.

Will it be too tiring?
The Chief Investigator recognises that engaging in lengthy discussion can be very hard for people with CFS/ME. Every effort will be made to accommodate these difficulties during the interview; you will be able to take regular breaks and if necessary the interview can be split across two meetings or undertaken over the telephone.

Will my taking part be kept confidential?
All the information about your participation in this study will be kept confidential. Further details and exceptions to this rule are included in Part 2.
Who should I contact to find out more?
If you wish to discuss the study further, without committing yourself in anyway please contact: (Chief Investigator and interviewer), Clinical Psychologist in Training, University of . Contact by leaving your telephone number with

This completes Part 1 of the Information Sheet, if this information has interested you and you are considering participating, please read Part 2 before making any decision.
Contemplating the Future in CFS
Information Sheet Part 2: Further Information

① What if I become distressed?
It is possible that some people may experience distress when talking about their experiences. If you feel distressed during the interview itself, you will be given an opportunity to discuss these feelings with the Chief Investigator at the end of the interview. If necessary you can also discuss any issues arising from the interview with Dr (Clinical Psychologist).

② Is it confidential?
Health professionals within the clinic will be aware that you have chosen to participate in the study. No one other than the Chief Investigator will have access to your questionnaire or interview responses, unless you request that this information is transferred to your clinic file. The Chief Investigator will hold your responses strictly confidential, with one exception: if you say something that leads her to believe that the safety of yourself or someone else is at risk, this information will need to be shared with the study’s Research Supervisor (Dr , Lecturer University of ) and Field Supervisor (Dr ) who will then act in accordance with Trust risk management contingencies. Before doing so, the Chief Investigator will speak with you about how she will do this.

③ What happens to my questionnaires/personal details?
All the information collected during the study will be coded using a pseudonym and have your name and address removed so that you cannot be recognised from it. All interviews will be tape recorded and then transcribed using pseudonyms to preserve your anonymity. Telephone interviews will be conducted and recorded via telephone recording equipment, from a private location where your discussions will not be overhead. All questionnaires will be stored securely in accordance with data protection laws regarding the storage of raw data, until they are destroyed (tapes will be destroyed after successful completion of the study’s viva, questionnaires and transcripts after 10 years of the Chief Investigator completing her qualification).

④ What happens to the results of the study?
This study is being undertaken as part of the academic requirements of the Chief Investigator’s Doctorate in Clinical Psychology, under supervision of Dr and Dr . Before taking part in the study you will be given the option of receiving a written summary of the findings and attending a focus group where you can express your views on the study’s findings, which will then be addressed within the final report, submitted to the University of by September 2007. An article about the study may be written and attempts may be made to publish it in a national psychology journal. No participant will be identified in any part of the final write-up or summary report.

⑤ Has the study been approved?
This study has been reviewed by the NHS Local Research Ethics Committee which raised no objection to it, and by the Research team at the

⑥ What if I am unhappy with the way the study was undertaken?
The Chief Investigator will make every effort to ensure that the study is undertaken to a high standard. However, the University has no-fault compensation insurance, covering claims for non-negligent harm and public liability insurance, covering public liability claims. If you have a concern about any aspect of this study, you should speak to the Chief Investigator who will do her best to answer your questions (for contact details see information sheet 1).

Contemplating the Future in CFS: A Grounded Theory Exploration of the Experience of Self and Contemplation of the Future Across Individuals with Chronic Fatigue Syndrome
If you remain unhappy and wish to complain formally, you can do this through the local Patient Advise Liaison Service (PALS) –

_Thank you for taking the time to read this._
APPENDIX 2

(Ethical Approval Letters)
18 October 2006

Dear

Living with Chronic Fatigue Syndrome (CFS): A grounded Theory exploration of the experience of contemplating the future for individuals with CFS (EC/2006/103/Psych) - FAST TRACK

On behalf of the Ethics Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the submitted protocol and supporting documentation.

Date of confirmation of ethical opinion: **18 October 2006**

The list of documents reviewed and approved by the Committee under its Fast Track procedure is as follows:-

<table>
<thead>
<tr>
<th>Document</th>
<th>Date</th>
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<tbody>
<tr>
<td>Application</td>
<td>04/10/2006</td>
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<tr>
<td>Insurance Proforma</td>
<td>04/10/2006</td>
</tr>
<tr>
<td>Summary of study</td>
<td>21/08/2006</td>
</tr>
<tr>
<td>Research Proposal</td>
<td>02/10/2006</td>
</tr>
<tr>
<td>Information Sheets 1 &amp; 2</td>
<td>02/10/2006</td>
</tr>
<tr>
<td>Consent Form</td>
<td>21/08/2006</td>
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<tr>
<td>Demographic Details Questionnaire</td>
<td>21/08/2006</td>
</tr>
<tr>
<td>Interview Schedule</td>
<td>21/08/2006</td>
</tr>
<tr>
<td>Approval Letter from the Surrey Research Ethics Committee</td>
<td>08/09/2006</td>
</tr>
<tr>
<td>Copy of the NHS Application</td>
<td>21/08/2006</td>
</tr>
<tr>
<td>Risk Assessment</td>
<td>21/08/2006</td>
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</table>

This opinion is given on the understanding that you will comply with the University's Ethical Guidelines for Teaching and Research, and with the condition set out below.

- That the Consent Form is amended to include signature of a witness as shown on the attached sample.
The Committee should be notified of any amendments to the protocol, any adverse reactions suffered by research participants, and if the study is terminated earlier than expected, with reasons.

I would be grateful if you would confirm, in writing, your acceptance of the conditions above.

You are asked to note that a further submission to the Ethics Committee will be required in the event that the study is not completed within five years of the above date.

Please inform me when the research has been completed.

Yours sincerely

Secretary, University Ethics Committee
Registry

cc:
Dear Clinical Psychologist in training

Department of Clinical Psychology

Our Ref:
8 September 2006

LIVING WITH CFS: A GROUNDED THEORY EXPLORATION OF THE EXPERIENCE OF CONTEMPLATING THE FUTURE FOR INDIVIDUALS WITH CFS

Thank you for attending the meeting of the Research Ethics Committee on 5 September to discuss the above study.

Issues discussed

(i) The Committee noted that under “What is the purpose of the study?” in the Information Sheet the text read “… the future and who they may become”. The Committee was concerned about the psychiatric connotation of the use of the words “who they may become” and invited you to explain their meaning. You said that you had in mind identity and achievement. The Committee suggested that you delete the words “and who they may become” and insert “and” between “themselves” and “the”. The Committee also felt that in the same paragraph the words “rather than attempting to establish causes of “CFS/ME” were unnecessary and suggested they be deleted. The Committee would welcome a copy of the revised version of the document as soon as possible.

(ii) The Committee was concerned about the potential for interviews to last for 90 minutes and the impact of this on participants. You explained that 90 minutes was an estimate of the maximum time it could take.
(iii) The Committee asked whether or not the severity of the syndrome would be an issue for any participants. You explained that all participants would be fully capable and recognised the potential ethical concerns if they were not.

(iv) Section A8 of the Application Form stated that your study aimed to widen the research focus towards including both women and men living with CFS. You clarified that statement by explaining that previous research on identity had focused on women.

Ethical opinion

The members of the Committee present gave a favourable ethical opinion of the above research on the basis described in the application form, protocol and supporting documents. The Committee was able to confirm the SSA-exempt status of the study.

Conditions of approval

The favourable opinion is given provided that you comply with the conditions set out in the attached document. You are advised to study the conditions carefully.

Approved documents

The documents reviewed and approved at the meeting were:

i) NHS REC Application Form, Version 5.1, dated 21 August 2006
ii) Your curriculum vitae, Version 1, dated 21 August 2006
iii) Dr's curriculum vitae, Version 1, dated 21 August 2006
iv) Letter from regarding insurance, dated August 2006
v) Letter from regarding sponsorship, dated 18 August 2006
vii) Peer review form, Version 1, dated 21 August 2006
viii) Information Sheet, Version 1, dated 21 August 2006
ix) Consent Form, Version 1, dated 21 August 2006
x) Interview Schedule, Version 1, dated 21 August 2006
xi) Demographic details questionnaire, Version 1, dated 21 August 2006

Research governance approval

You should, as you know, obtain research governance approval from NHS Trust before commencing any research procedures. Where a substantive contract is not held with that organisation it may be necessary for an honorary contract to be issued before approval for the research can be given.

Membership of the Committee

The members of the Ethics Committee who were present at the meeting are listed on the attached sheet.
Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

Yours sincerely

Co-ordinator

Enc

Copy to:
APPENDIX 3

(Research and Development Approval)
Dear

Re: Living with CFS: A Grounded Theory Exploration of the Experience of Contemplating the Future for Individuals with CFS.

Thank you for sending us all the information relating to your research as part of your post graduate education.

The researcher aims to interview patients selected from those attending a group for CFS at the [Institution]. The proposed study is supervised by your academic supervisor.

The Trust is supportive of this study as proposed subject to approval from a NHS Research Ethics Committee.

Yours sincerely

Head of Healthcare Standards
APPENDIX 4

(Consent Form)
Contemplating the Future in CFS

Consent Form

(Chief Investigator), Version 2, 21st October 2006

Please tick the boxes below to show that you the following procedures have been completed.

I, the undersigned, I agree to take part in the above study. □

In doing so, I confirm that I have read and understand the information sheet dated 21/08/06 (Version 1) for the above study. □

I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. □

I understand that the Chief Investigator is conducting this research as part of the requirements of a Doctoral Course in Clinical Psychology at the University of . □

I understand that my participation is voluntary and that I am free to withhold information or withdraw at any time, without giving any reason, without my medical care or legal rights being affected. □

I understand that the data obtained within the study will be held in accordance with the Data Protection Act and that information disclosed during my contact with the Chief Investigator will remain confidential (with the exception to circumstances outline in Part 2 of the information sheet dated 21st August 2006, version, 1). □

I understand that pseudonyms will be used when referring to any of my comments within the data analysis and write up. □

I would like to have a brief summary of the results of the study at a later date, please circle. Yes No

I would like to attend a focus group to discuss the results of the study, please circle. Yes No

Name of Participant (BLOCK CAPITALS)   Signature   Date

In the presence of (name of witness) (BLOCK CAPITALS)   Signature   Date

Chief Investigator (BLOCK CAPITALS)   Signature   Date

1 copy for participant; 1 copy for Chief Investigator site file.

Contemplating the Future in CFS: A Grounded Theory Exploration of the Experience of Self and Contemplation of the Future Across Individuals with Chronic Fatigue Syndrome
APPENDIX 5

(Demographic Details Questionnaire)
Contemplating the Future in CFS

Demographic Details Questionnaire

Name:

Gender, please tick: Male □ Female □

Date of Birth: Age:

Please describe your ethnicity:

When did you first develop CFS/ME?

□ 6months – 1 year ago
□ 1 – 5 years ago
□ 5-10 years ago
□ 10 years ago+

Briefly outline any previous medical/complementary treatments taken since diagnosis:

□ CBT
□ Counselling
□ Psychotherapy
□ Fish Oils
□ Acupuncture
□ Homeopathy
□ Physiotherapy
□ Other please specify: ........................................................................................................
........................................................................................................................................
........................................................................................................................................
........................................................................................................................................

Please tick your highest academic qualification?

□ GCSE/CSE
□ O-level/A-level
□ NVQ/Diploma
□ Degree
□ Post Graduate Qualification
□ Other please specify: ........................................................................................................

Please describe the nature of your occupation prior to developing CFS
........................................................................................................................................
........................................................................................................................................

Contemplating the Future in CFS: A Grounded Theory Exploration of the Experience of Self and Contemplation of the Future Across Individuals with Chronic Fatigue Syndrome
Version 1 (21/08/06) continued.

Please describe your current employment circumstances

☐ Part-time employed, if so please state nature of occupation.................................

☐ Full-time employed, if so please state nature of occupation.................................

☐ On sick leave
☐ Receiving disability benefits
☐ Retired
☐ Other please specify.................................................................................................

Please describe your current relationship status

☐ Single
☐ In a relationship but not co-habiting
☐ Co-habiting
☐ Married
☐ Separated/Divorced
☐ Widowed

THANK YOU FOR YOUR PARTICIPATION

Contemplating the Future in CFS: A Grounded Theory Exploration of the Experience of Self and Contemplation of the Future Across Individuals with Chronic Fatigue Syndrome
Contemplating the Future in CFS: A Grounded Theory Exploration of the Experience of Self and Contemplation of the Future Across Individuals with Chronic Fatigue Syndrome
Contemplating the Future in CFS

Version 1, August 2006

Interview Schedule

Preliminaries
Thank the interviewee for agreeing to take part.
Introduce myself and the nature/aims of the research topic.
Explain the confidentiality procedures, and when they must be broken, e.g. risk and duty of care.
Ensure you have obtained written consent to participate, to tape record the interview and use pseudonyms in the write-up.
Address any further questions the interviewee wants to ask.

Illness History and Details

1. Why did you originally come to the ___________Clinic?

2. (Only if they mention CFS): When did you first develop CFS?

3. How have things been for you since that time?
   Can you describe a typical day so that I can try and understand what it is like to live with CFS?
   Does anything make things harder/help?

Current Self-Concept

4. What do you think and feel about your life now?

5. How do you see yourself at the moment?
   How would you sum yourself up?
   How do you think/feel about yourself?
   What matters to you, what is important to you?

Contemplating the Future?

6. How do you envisage your life generally over the next 2,5, 10 years (as appropriate)?

7. What are your hopes/fears for yourself across the next 2,5,10 years?
   What sort of person would you like to become/avoid?
   What are your goals?

8. How would you compare the person you hope to become, with how you are now?

9. Looking back, how would you compare these expectations to those held before you developed CFS?
   Do you see your future differently/the same, how?

10. Why do you think your expectations for the future have changed/continued in this way?
    Has anything caused this change/continuity, if so what?

Contemplating the Future in CFS: A Grounded Theory Exploration of the Experience of Self and Contemplation of the Future Across Individuals with Chronic Fatigue Syndrome
11. What was it about these experiences/events/people that led to change/continuity? 
   *How did these things affect you?*

12. What is it like to think about these things? 
   *Is this something you have thought about before?*  
   *How does it make you think/feel/do?*

13. Does it always feel this way? 
   *If no, what is different about times when you think/feel differently?*

**Finishing Off**

14. Is there anything about the experience over the last _______ months/years that you have valued?  
   *What was it about this that you found important?*  
   *How did it affect you?*

15. Have you learnt anything new about yourself/grown in any way?  

16. (If new learning has occurred) Have these insights helped you in any way?  

17. Is there anything else you think I should know to help me understand your experiences better?  

18. What has it been like to talk about yourself in this way?  

19. Is there anything you would like to ask me?  

**General Prompts**  
Can you tell me more?  

When you said _____ what did you mean?
APPENDIX 7

(Amended Interview Schedule)
Contemplating the Future in CFS

Amended Interview Schedule (Amendments in Grey)

Intro see prompt sheet

Illness History and Details

1. To begin with, I was wondering if you would mind telling me a little about yourself, starting with why you are attending the _______________ Clinic?

2. (Only if they mention CFS): I'd be interested in knowing what having CFS means to you?

   Can you describe a typical day so that I can try and understand what it is like to live with CFS?

   Does anything make it harder/help?

   How do you manage/cope/get by- if avoidance/acceptance comes up explore more about how/when/why?

Current Self-Concept

3. What do you think and feel about your life now?
   Where are you now?

4. How do you see yourself at the moment?

   How would you sum yourself up?
   How do you think/feel about yourself?
   What matters to you, what is important to you?
   Why do you see yourself this way?

5. Have you always seen yourself this way?
   What has informed this shift/continuity
   How does it affect you?

6. (if others have been mentioned) How do you think others see you?
   Has it always been this way?
   Why do you believe/think this?
   What is it like to think this?

   You’ve talked a lot about (insert physical things where appropriate) How do you see your body?

7. How does this compare with how you thought about you’re body before?
   How do you understand this shift/continuity?
   What has been important in influencing this view?
What is it like to think this way? How does it affect you?

8. What would it mean to think about your body differently/how would things have to be?

(These questions are designed to explore both relationship to the body and circumstances informing this and also acceptance without use of the word of 'acceptance')

Contemplating the Future?

9. Thinking back to where you are now, where do you think this will lead you over the next 2,5, 10 years (as appropriate)?

What are your hopes/fears for yourself?
What sort of person would you like to become/avoid?
What are your goals?

10. How would you compare this person (you hope to become), with how you are now?

11. Looking back, how would you compare these expectations to those held before you developed CFS?

Do you see your future differently/the same, how?

12. (Only if change/continuity mentioned) Why do think your expectations for the future have changed/continued in this way?

(only if they mention causes) What was it about these experiences/events/people that led to change/continuity?
How did these things affect you?

13. What is it like to think about these things/the future?

Is this something you have thought about before?
How does it make you think/feel/act?

14. Is it always this way?

If no, what is different about times when you think/feel/act differently?

Finishing Off

15. Is there anything about the experience over the last________ months/years that you have valued?

What was it about this that you found important?
How did it affect you?

16. Do you think you have changed in any way not already mentioned?

If negative only: Have you learnt anything new about yourself/grown in any way?
(If new learning has occurred) Have these insights helped you in any way?
17. Is there anything else you think I should know to help me understand your experiences better?

18. What has it been like to talk about yourself in this way?

19. Is there anything you would like to ask me?
APPENDIX 8

(Example of Coded Interview)
**Interview 5: Jim**

CI: Chief Investigator

CI So I wonder if to start with you'd mind telling me a bit about how you came to be going to the [names clinic]?

Jim Um... oh I can't... I remember how it came about... it was obviously in the early stages I went to my GP and had... well I didn't understand what was going on with me at the time and nor did they basically I mean they tested me for all sorts of things um polymyalgia, fibromyalgia all this, glandular fever and all this blood tests and when they all come negative I had to go and see a chap at [names hospital] and he was the one that actually said you've got chronic fatigue.

CI Right

Jim Um.

CI And when was that.

Jim Well I first... it's two years now but I first had symptoms in [names date approx 2 years ago] when I was playing golf I felt something not quite right 'cos I played a lot of golf towards the end of it and I was feeling absolutely shattered and I never recovered really since then er... so I did the normal thing had a week off work 'cos I thought I had the flu... slept most of that, went back to work... had a week off, went back to work on the following Monday, by the Thursday I had to give in again it just wasn't improving... so I went back to the doctors and they signed me off for a fortnight and I've been off ever since.

CI Right.

Jim They said... initially they diagnosed depression which scared me a bit because I've been depressed before over a divorce and I didn't want that, you know. But anyway I was then thinking of all sorts of things that were wrong with me you know as you would and then when I was diagnosed with Chronic Fatigue although it's inconvenient it was a relief in one way as well.

CI Umm

Jim Um but I can't quite remember how I became involved with the [names clinic].

CI Don't worry if you can't remember that's fine.

Jim I remember I was booked up for 7 sessions like it was around Christmas time in [names year] and I think we had three or four before Christmas and then a break and then three afterwards or whatever it

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**Line by Line Coding**

**Focused Codes for Each Section**

- Seeking medical help
- Undergoing repeated medical tests
- Difficulty identifying a biological cause for illness
- Receiving diagnosis
- Recounting illness onset
- Difficulty undertaking sporting activities
- Not recovering
- Taking time off work
- Returning to work
- Experiencing no improvement
- Being signed off work
- Receiving a psychological explanation for illness
- Fearing psychological explanation for illness
- Considering multiple explanations for illness
- Feeling relieved after diagnosis
- Difficulty recalling initial contact with clinic
was, I can't remember if I was referred up there by my GP...I'm not sure.

**CI**

Don't worry...it's just kind of an opening question to get people started, it doesn't matter if you can't remember..... I wonder if you could kind of describe to me a bit about what CFS means to you, how it affects you....um what it's like living with it?

**Jim**

Err...frustrating is probably the biggest thing about it and that people keep saying oh you will get over it, you will get over it but.

**CI**

Is that professionals or friends?

**Jim**

Everybody, yeah professionals do say that 'cos I um when I was off sick from work I had to go and see occupational health also you know regular and er the lady there that was seeing me kept saying to me you know you will beat it because you want to to you know she sees people that were a lot more negative than I was being.

**CI**

Is that a help when people say that or...

**Jim**

[interjects] it can be but it's also a frustration, it's like having a prison sentence

and not knowing how long you've got

and you know I do meet people that have recovered from it because I'm a member of [names support group] and

that's got quite a few people in there that are not fully recovered but 90%...they can live sort of a normal life um just be careful because they do have a relapse sort of know and again but they're more or less over it but then er I've meet people that have had it for 20 years and have still got it and you sort of wonder which one am I going to be. It is yeah the uncertainty of not know how long am I going to be like this but if someone were to say to me tomorrow you're never going to get better, this is what you're life is going to be like till you die or something...perhaps you would just accept it and it's this not thinking that next week I might be alright.

**Jim**

It's different.... some days you accept it easier than others...

I do accept it better now than I did in the early stages because it's I found it so frustrating...I'd feel like throwing things against the walls...partially because I didn't understand what was going on with me....I'd always been quite...I'd played football when I was younger and then I played golf that was my thing and I lost all that sort of thing...not just the playing it's the social side of it as well

**CI**

Difficulty recalling referral to clinic

**Experiencing frustration**

**Being told recovery is certain**

**Being told recovery is uncertain**

**Receiving professional advice**

**Linking recovering to mental attitude**

**Experiencing frustration**

**Feeling imprisoned by illness**

**Regarding prognosis as uncertain**

**Meeting people who have recovered**

**Attending illness related groups/organisations**

**Viewing recovery as partial**

**Seeing relapse as inevitable**

**Meeting people who have not recovered**

**Wondering whether recovery is possible**

**Experiencing uncertainty regarding prognosis**

**Imagining that recovery is not possible**

**Seeing acceptance as dependent upon certainty**

**Shifting levels of acceptance**

**Increasing acceptance**

**Difficulty accepting ill health**

**Difficulty understanding the illness experience**

**Defining pro-illness self by**

**Defining pro-illness self by**
so I feel trapped in a certain way I’m in a little world like that my little world and the bigger worlds out there...I can’t get out there I’m stuck here you know and people keep saying well...like I want to see my mum and that on...I come from a big family...on mother’s day and they were all telling me how well I was looking and all that.

CI And what’s it like when people...
Jim [interj] I had to tell them to shut up in the end because I said...I’ve been feeling poorly...over Christmas I picked up a bit I was feeling a bit better and it had all sort of gone...collapsed again and went backwards...I’d been feeling really bad the two weeks previous to mothers day and err for them you know to go...they were being...only telling me what they thought...they were all saying how well I looked so in the end I said shut up ...I feel absolutely diabolical, I might look alright which is part of the problem with this illness.

CI When they say to you, you look really well what goes through your mind?
Jim That I don’t feel very well, you know, if only you could feel what, how I’m feeling and it’s frustrating,
you can’t get it across to people but
because you don’t look ill if you know people come to visit they expect you to look ill um and I say to them you know if you spend some with me then you’d realise, it’s not quite as it looks you know if you saw me trying to mouch about, do a bit of gardening or do a bit of washing up or whatever you’d realise that there’s... ‘cos that’s what happens I feel OK like sitting here but if I went and to cut the grass something like that I’d have to do that in about five attempts I couldn’t...where as it used to be an hours work one go, I have to break it down I do a bit then I have to rest but that’s the cycle [Jim’s phone rings and the tape is broken so that he can answer it].

If I know that I’ve got to be somewhere I can sort of plan to conserve my energy and I’ll have an early night Tuesday night to make sure I’ll be up and I know then I’ve got to go and have this MOT by late morning I should be back and I can rest again and that’s like I have to try and programme it sort of thing and being invited to social functions as well I have to be... ‘cos that chap phoning up his wife’s going to be 40 and we’re invited to that and I’ve already spoken to him and said look you don’t mind if I just come along for an hour, two hours and said whatever suits you know um ‘cos I don’t like a lot of noise either that gets to me.

CI You’re quite sensitive to sound?
Jim Um yeah...I never was like that before but I just find it gets on top of me I’ve had enough of it...I want

activities
- Valuing social contact associated with pre-illness interests
- Feeling trapped
- Feeling isolated from wider world
- Interpreting the perceptions of others: Being seen as ‘well’
- Feeling unwell; Experiencing improvement
- Relapse following improvement
- Experiencing a contrast between inward and outward presentation
- Expressing anger towards others
- Perceiving a conflict between internal and external states
- Wanting others to understand
- Experiencing frustration
- Difficulty making others understand
- Seeing understanding as hindered by ‘healthy’ appearance
- Needing time to make others understood
- Trying to undertake activity
- Breaking activity into chunks
- Comparing current and pre-illness capacity
- Breaking activity into small chunks
- Balancing activity with rest
- Resting prior to activity; Resting following activity
- Being invited to social occasions
- Shortening social engagements in advance
- Disliking loud noises

activities
- Seeking others understanding
- Seeing understanding as hindered by ‘healthy’ appearance.
- Managing symptoms by breaking activity into chunks
- Balancing activity with rest
- Managing symptoms through rest
to get out so.

Cl You mentioned that um some days it's easier to accept things than others and I guess I was just wondering what was different about the days when it's easier or harder to accept things.

Jim I suppose it's days when I'm feeling better within myself I've never really thought about it you've just put it... but some days I am more frustrated than others so it's just... I don't know.

Cl So is it the better days when it's easier to accept it or the better days when it's harder to accept it.

Jim No when it's easier.

Cl Ok.

Jim Yeah I can accept where I am in this life and I tend to think about other people who are worse off than me and I try and do that and I have walks around the village which is nice you know and what I do is I walk half way round and sit by the duck pond feed the ducks and the walk back and I think well there's a lot of people who would like to be doing this um and I'm sat there sort of trying to take in the niceness of it and listen to the traffic roaring, thinking everyone's whizzing around from here to there and I'm being able to sit...

Cl So you're able to kind of enjoy the...

Jim Enjoy the moment, which is something that [names facilitator of group] talked about mindfulness is it.

Cl Yeah.

Jim And I do try and take it on board that I could be a lot worse off than this... I know it's inconvenient and I'll be frustrated with it and I do want to break out into the big wide world go back to work, go back to sport be normal so to speak but you know it could be worse.

Cl How do you get by day to day...what do you do to cope with things?

Jim I try and do little bits and pieces like the gardening um I try and cook the food something like that um for when my boys my young son comes over there I try and do bits and pieces to contribute 'cos otherwise I feel blooming useless that I'm not contributing anything...

I've got a partner who goes to work full time and she comes home here and tries to do the house work you know everything you just feel a bit like er on a loose whatever, you know you can't contribute as you would like to... and she tells me not to worry about it and all that but it does bother me a bit so I try and do like little bits and pieces like say like the washing up, bits of cooking anything I can really, so I'll go for a walk round the block, I'll try and potter around in the garden 'cos that hedge has got to be cut this week and I borrowed the hedge trimmers off my brother in law and I'll have a go... it might take me ten goes but I'm not... it's a... I'll look at it and I'll think I've achieved it as well.

I have to be so careful because if I overdo it... it knocks me out for 2 or three days it just flattens me

Difficult tolerating noisy environments

Linking acceptance with better days

Shifting levels of frustration

Linking acceptance with better days

Accepting current circumstances

Recognising others worse off than self

Appreciating positive aspects of illness experience

Being able to sit and appreciate

Enjoying the moment

Experiencing illness as inconvenient

Seeking a return to pre-illness roles/interests

Linking return to pre-illness function with normality

Undertaking small tasks

Wanting to contribute

Feeling useless

Equating inability to contribute with worthlessness

Receiving re-assurance from others

Contributing through activity

Identifying achievable tasks

Breaking tasks down

Seeking a return to pre-illness roles/interests
and I can't do anything at all.

CI So it's balancing...it sounds like you get a real sense of achievement though from when you are able to do things.
Jim Yeah, yeah but then it knocks me sideways and that sort of winds me up as well...I haven't done that much really, I've cut the grass so what but it's accepting you can't do what you used to be able to do.
CI What's that like to have to try and accept that?
Jim Horrible.
CI Horrible...
Jim Um...yeah I just want it all to be over now you know it's [X] years and I've had enough of it and it feels like some one's stuck a big syringe in me and taken my energy.
CI OK...I wonder if you can tell me a bit about how things are for you now...how you see yourself, how you think about yourself at the moment.
Jim Er...I think I just take one day at a time really because I can't plan anything very much too far in advance because you never know how I'm going to feel but um I'm getting married next week so that's a big step....
CI Wow congratulations...
Jim Which is a big step as well 'cos I mean [names wife] should be here more 'cos she's sort of running two properties at the moment the flat she shares with her boys and this where she spends most of her time so that's a step in the right direction...that's another sort of to settle me down a little bit but I just feel I can't sort of look too far into the future because I don't know how I'm going to feel.
CI What about how you'd sum yourself up, kind of how you'd see yourself at the moment, Jim [Long pause...]
CI or what matters to you?
Jim Um it matters to me to try and contribute, I mean even though I'm not feeling great...I want to be part of it if you know and not just allow [names wife] to do everything, although she would do everything if I let her.
CI Why do you think...is it that something that's always been important to you?
Jim Um yeah I've always been sort of 50:50 you know when I was married and all that I wouldn't sort of say that's your job and that's my job I'd mix in we'd do everything together...um and having that sort of taken away from you is another part of the frustration.
CI How does that leave you feeling...not being able to contribute as much as you'd like?
Jim Well frustrated really...a bit sad about it....the other thing I do is rest a lot and sleep a lot...I don't see

Pacing self
Linking over-exertion with relapse
Gaining achievement through activity
Linking over-exertion with relapse

Perceiving 'costs' as outweighing activity
Accepting reduced levels of activity
Difficulty accepting reduced levels of activity
Seeking recovery
Feeling depleted of energy
Seeking recovery
Taking one day at a time
Difficulty planning for the future
Getting married.

Difficulty contemplating the future
Experiencing uncertainty about future health
Difficulty contemplating the future

Wanting to contribute
Reluctance to let partner contribute
Perceiving pre-illness self as a contributor
Valuing equality in relationships
Experiencing a removal of equality
Experiencing frustration; Feeling
the mornings very much at all um and then I get annoyed with myself about that...
I think I’m sleeping my life away you know, you can’t... I mean I sleep 14-16 hours a day which is the wrong way round... you should sleep 8 and be awake 16... it’s almost like it’s back to front... and I have to accept that’s what I’ve got to do at certain times... ‘cos last night I just became... we had dinner, which I managed to do and then half an hour later I said to [partner] look I’ve got to go to bed and I was asleep before she even came up you know I didn’t speak to her until this morning and I can’t remember then I said was I asleep when you came upstairs... then I got up this morning, she was going to wake me at 12 but I actually got up at 11.30 which is a hell of a lot of time to spend... if I’m not sleeping I’m resting [Jim stops to take another phone call].

CI We were talking about how you kind of see yourself now... I don’t know if that’s an easy question to answer or a really tough one?
Jim Um... how do you mean in what way?
CI Um I guess kind of how you’d describe yourself or how you’d sum yourself up.
Jim Dunno... just frustrated, sad sometimes um it is mainly frustration at being in this feeling trapped in this little world and you can’t get out of it and there’s no answer to it.
CI Does that affect you day to day... is it a continuous sort of thing...?
Jim Constant sort of thing yeah... I mean you know I’ll sort of swear to myself sometimes you know... I don’t know if I’ve just done something some menial sort of task and it’s drained me... I feel like I’ve got that much energy [moves index finger and thumb a small distance apart] and every time I do something there’s just nothing and now do I sort of curse to myself how long am I going to be feeling like this for and I haven’t done anything I shouldn’t be feeling like this but that’s just the way it is... I don’t know how to explain myself properly.

CI How did you see yourself or how would you have summed yourself up before the Chronic Fatigue?
Jim Um I was quite a sporty, happy go lucky sort of person always worked had the same job for [X] years sort of thing I was like a steady Eddy sort of guy... didn’t like change too much um I knew were I was I... towards the end I wasn’t enjoying my job although I had been previous... I suppose for the last year or so it was getting a bit stressful... um I dunno I liked a laugh and a joke and a few beers, just to go and meet in the pub [incredible] to have a laugh playing golf and a few beers afterwards... it was quite a nice social activity um just what I consider to be normal really and now I have to... I can’t think oh I’ll just go and just do that... I’ll go and do that.. I have to plan it a bit to make sure I can go and do that, you know ‘cos I’m thinking of going up the [names club] tomorrow evening ‘cos they plan on a evening after work, which I used to do, I thought if it’s like this I might drive up there and just say hello to them, walk around a couple of holes just to keep in contact really, people have been telling me to do that for ages.

sad; resting
Sleeping until afternoon
Linking frustration with the need to rest
Perceiving self as missing out through resting
Difficulty balancing sleep/wake patterns
Perceiving sleep/wake patterns as reversed

Perceiving self as frustrated
Perceiving self as trapped
Expressing frustration towards limited energy levels
Perceiving energy resources as limited
Questioning the future duration of symptoms
Perceiving fatigue as unjustified
Difficulty explaining self

Perceiving pre-illness self as active
Perceiving work role as important to pre-illness self
Perceiving pre-illness self as dependable
Experiencing stresses at work
Linking pre-illness interests with social activities
Perceiving pre-illness self as normal
Difficulty engaging in spontaneous activity (post-illness)

Linking frustration with the need to rest
Difficulty balancing sleep/wake patterns
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Planning activities
Seeking to continue pre-illness activities
Trying to retain social contacts
Receiving encouragement to engage in social activity.
Linking encouragement from others to healthy appearance.
Receiving negative comments from others
Others expressing illness opinions covertly
Being disbelieved by others
Trying to remain calm
Seeking to understand others points of view
Perceiving self as appearing healthy
Linking negative comments with 'healthy' appearance
Perceiving others as continuing to relate to pre-illness self.

Others expressing disbelief at diagnosis
Others implying diagnosis is related to psychological factors
Telling self that others don’t understand
Interpreting feelings of partner
Expressing distress
Difficulty explaining illness experience to others
Others implying that recovery is linked to attitude
Justifying illness experience as unwanted
Comparing self to others;

CI

Is this kind of friends and people trying to get you to go out and do things...what’s it ...

Jim [interjects] some of which puts me off because I don’t look ill.

CI

Can you tell me a bit more about that....

Jim

Well I used to get the negative sort of comments in the early days...even from my family,...I remember my elder brother we went...we had a walk round the pub and when we came back I heard him say to [names partner] while I thought I was out of ear shot...I heard him say to [names partner] my partner it’s an act isn’t it...and I thought to myself you just don’t understand...I'm not going to get annoyed about it because I'm not sure how I would view it if it was the other way round because I didn’t look any different and people are used to you being how you were and they can’t quite grasp it they want to just tell you pull yourself together you know, you know...if you could.

CI

Has that happened a lot with people saying or implying it’s an act?

Jim

A few times...the guy who used to run the pub...I went round there and I was reading a book on Chronic Fatigue coping with Chronic Fatigue and he asked me what I was reading and I showed him this book and he said what are you reading that for and I said 'cos I'm suffering from it imminently and he said Oh I don’t believe all that and I said well, I hope you don’t get it then and he said well I won’t get it because I don’t want it and I said well if it was that easy...

CI

What’s that like having to sort of come up against that reaction...

Jim

Well I just have to sort of remember that they don’t understand...it’s more hurtful I think for [partner] 'cos she’s seen what I’ve been going through you know in the early days I’d end up in tears sometimes and I couldn’t explain it to people how bad I was actually feeling and er even my brother in law who lent me the hedge trimmers he said I feel like saying just getting hold of you and shaking you and saying pull yourself together you know...I said well [names brother in law] if it was that easy I’d do it I don’t want to feel like this who would want to be mooching around like an old man...that’s what I...I walk around slowly you know...there’s just no energy there at all.
Contemplating the Future in CFS: A Grounded Theory Exploration of the Experience of Self and Contemplation of the Future Across Individuals with Chronic Fatigue Syndrome

Why do you think they think that way.

Because you don’t look ill…people relate people being ill to looking bad…if I came out in a rash all over they’d probably say oh you’ve got Chronic Fatigue but then because you haven’t…but then people have migraines you can’t see that can you and people believe all that don’t they um but part of being in the (names support group) as well is quite good, because you are dealing with people that understand where you’re coming from they know what it’s like.

And that’s been a help…?

Yeah, rather than talking to people that don’t…and I do start thinking to myself well what would I be like if it was like my brother that had been ill and I say to him well you look alright you know…it is a difficult one because it’s all inside really it’s invisible and we’re the only ones the people who have got it that are living with it and I didn’t like realise how rife it is really in society…I’d hardly heard of it…I’d heard of yuppy flu and all this before but it wasn’t until I went down with it, was diagnosed with it and started looking into it that you realise how many people there are in the country…my GP although she was sympathetic…she couldn’t really offer me anything apart from anti-depressants.

And what was it like being offered antidepressants…

I knew I had to have them ‘cos this illness is depressing but actually at this moment in time I’m trying to wean myself off them…I’m taking one every three days now instead of one everyday and trying to spread that out…but (names partner) notices when I’ve not been taking them you know I get a bit touchy and I don’t realise I’m doing it but she realises the change in me, so I have to be careful I can’t just stop um but after I’d seen that professor at (names location) and he obviously emailed my GP to give him what is opinion was and all that and I had to go back and see her again and then I said to her oh I’ve got this unwanted identifying with older age group

Comparing self to others; identifying with older age group. Experiencing total lack of energy.

Interpreting opinions of others; Linking others disbelief to healthy appearance. Seeing understanding from others as dependent upon observable physical illness. Gaining understanding through illness related organisations.

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Comparing self to others; identifying with older age group. Experiencing total lack of energy.

Interpreting opinions of others; Linking others disbelief to healthy appearance. Seeing understanding from others as dependent upon observable physical illness. Gaining understanding through illness related organisations.

Distinguishing others on the basis of illness understanding. Putting self in others shoes; Questioning validity of others perceptions. Perceiving difficulties as invisible Perceiving difficulties as widespread

Recalling pre-illness knowledge of condition. Recalling media labels for condition. Awareness of others with similar difficulties Being offered psychological treatment approaches

Justifying use of psychological medication. Reducing medication intake Partner aware of changes in mood. Becoming more sensitive Lack of awareness of personality changes Being cautious with medication

Recalling media labels for condition. Being offered psychological treatment approaches

Questioning the validity of others perceptions

Justifying use of psychological medication

Recalling media labels for condition. Being offered psychological treatment approaches

Questioning the validity of others perceptions

Justifying use of psychological medication
ME where do I go
and she said well I can’t do anything
and I said well are there any groups that I can get in touch with all that and she said well I don’t know
and I said to her well what do I do and she said well are you on the internet and I said no, she said well
you’ll have to go to the library in [names location] and look it up...you’d think at least they’d have a bit of...
"cos there’s more of it now than there’s ever been I suppose, yeah you’d think they would know
about the [names support group] or anything like that that they can refer you to so that when there is a
group you can join perhaps that would do you can join so that you’re not just on your own...you’re not
isolated there are people that understand and you need a bit of that...although I was relief in a way that I
had ME it had been diagnosed,

I also felt sort of a bit alone what do I do next,
how long am I going to be stuck like this for ‘cos I don’t think....there’s no sort of average time...it’s an
individual..you know it could be one year it could be 20 years um.

Cl What about things with other people how are things kind of with other people generally...you talked
about that you get the negative comments some times has that changed things or relationships....

Jim I think the longer it’s gone on people have began to realise they may have initially thought ‘cos they
do’t understand it probably snap out of it and all that

but I think the longer it went on the more they thought blimey there is something wrong here you know
Jim’s* not like this and the sympathy sort of came in a bit more then er but I’ve also been disappointed
with people that you think would come and visit you or at least phone you and they don’t ...and I sort
of think to myself if it was the other way round I’m sure I’d be in touch with you a bit more you know,
people that you think are your close friends...yeah I’ve got one my best mate...he phones me
every week and he’d come over every two or three weeks to come and see me but then there’s other
people that you know, blimey it’s been two years and I’ve had one visit from one of the chaps and it
disappoints you it doesn’t make you angry it just disappoints me really.

Cl Disappointed in them?

Jim Yeah, you know not even a phone call, that’s all it would take that they might even be thinking about
you, you know...I don’t want them to feel sorry for me or anything like that but just come and see me
or phone me up or ‘cos I’m sure if it was the other way round I would do that ‘cos you need people as
well, you need a bit of support um or and I don’t get the negative comments like I had in the beginning

Receiving professional opinion
Contacting GP
Requesting support
Receiving no support
Seeking contact with
others/organisations
Being given responsibility for
accessing support
Seeking understanding from others
Seeing contact with others
Feeling relieved (following
diagnosis)
Feeling alone (following diagnosis)
Contemplating prognosis
Difficulty predicting prognosis

Receiving increasing understanding
from others
Interpreting perceptions of others;
perceiving others as seeing illness
as within control
Perceiving that others see self as
changed by illness
Experiencing changed relationships
Questioning changed relationships
Putting self in others’ shoes
Receiving regular contact from
others; Feeling disappointed in
others

Feeling disappointed in others

Feeling forgotten by others
Avoiding sympathy
Comparing self with others
Needing social support

Questions professional
knowledge of condition
Seeking contact/understanding
from others with CFS
Feeling alone (following
diagnosis)
you know people understand now although I’m surprised...I should’ve be surprised but the more people I talk...I’m surprised about the amount of people I talk to who know someone whose had ME you know even up this road number [gives number] and number [gives number] the women work with people that have had ME and who have recovered so you know, that surprised me a bit initially you just talk to people who say oh I know someone and I saw an old school friend of mine last week in [names location] and he was with his wife and I knew his wife had suffered with ME but I didn’t know until I became ill with it and someone told me and his wife was actually with him and so we had a bit of a chat for twenty minutes and that was quite good 'cos she understood what I was saying um I felt a bit sorry for her because she had her...she was struck down with it when she had young children which you can’t just go to bed like I can. I can just shut down if I want [indiscernible] I have to rest, but when you’re running a family it’s not so easy is it or dunno.

CI: What about you kind of think about your body now through having CFS...has that changed at all or stayed the same...?

Jim: Well I try to er change my diet a bit you know I try to um ‘cos you read different things all over the place about it um ‘cos cheese I’d have cheese everyday of the week, now I try and have cheese at the weekend as a treat sort of thing ‘cos I read somewhere that someone was put on a diet which didn’t involve cheese and I try to have sort of yoghurt, try to put some healthy you know fruit and veg stuff into my body...um trying to do what I can do you know for myself drink less, eat better, trying to go for walk round the block everyday even if I don’t feel like it just try and help myself with the little bits I can um but that...I’ve been doing that sort of since Christmas time and I haven’t really noticed the benefits of it yet so that gets a bit of sort of then you think to yourself what’s the point...I might as well go and drink a bottle of wine or whatever um and then I’ll get back on it again...I know it’s sensible...to try and lose it...I’ve lost nearly a stone and I’ve got another couple to use...it hasn’t made me feel any better yet but it can only be good for me that’s what I try and keep thinking to myself although I’m not seeing the benefits of it, or I don’t feel I am, it’s got to be better hasn’t it...‘cos before I wouldn’t bother to cook or anything.,

Feeling understood
Increasing awareness of illness in others
Learning about others with same illness
Feeling understood by others with illness
Comparing self with others
Feeling lucky compared with others
Family responsibilities hindering capacity to rest

Managing symptoms through altering diet
Reading about influence of diet on illness
Regulating diary intake
Managing symptoms through regular activity
Seeking to maintain activity despite symptoms
Difficulty seeing the benefits of lifestyle changes
Feeling tempted to abandon efforts at symptom management/give up
Difficulty maintaining motivation
Maintaining motivation by self-talk
Questioning effectiveness of symptom management
Identifying post-illness changes
Wanting to help others
Identifying pre-post-illness changes

CI: So that’s something that’s changed....

Jim: Yeah ‘cos having [names partner] here quite a lot I want to try and do a bit of something for her ‘cos before I’d only cook properly even before I became ill, ‘cos I got divorced at the end of [names date] I spent quite a lot of time here on my own apart from when the boys came over every other weekend and
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then I used to cook for them but other times I'd have something like cheese and biscuits or a toasted cheese sandwich and cheese with pickle... 'cos it was so easy... I have tidied my act up a bit and I think that can only do me good in the long run and I'm fortunate to have someone like [names wife] around 'cos people who live on their own with this... I don't know how they cope.

Eating for one
- Improving eating habits
- Feeling lucky
- Acknowledging need for partners support
- Comparing self to others;
- Questioning capacity to cope alone

Being treated as an equal
- Receiving support from partner
- Attempting to support partner around home
- Being encouraged not to undertake household tasks
- Collecting partner from work
- Partner unable to drive
- Partner expressing concern
- Feeling indebted to partner
- Resting to ensure that partner can be supported

Wanting to contribute
- Feeling indebted to partner

Questioning capacity to cope alone
- Lowering standards for activity
- Perceiving life as changed by illness
- Inability to maintain pre-illness activity levels

Increasing acceptance of lowered standards
- Expressing frustration
- Difficulty understanding illness experience
- Appreciating the need to lower

CI How does [partner] being around help you...?
Jim We get on very, very well anyway, we never argue um... as I say we just treat each other as an equal and she does everything she can for me you know... she does all the house work... all the washing and ironing you know the stuff that I can't really do... I might have a go at doing a bit of polishing now and again but she tells me not to bother you know but I know having her around makes it so much easier for me er... but she works shift work... like today she's doing 2.30 till 10.30 and then I'll have to go into [names location] to pick her up.

CI 'cos she's not she's having driving lessons at the minutes 'cos she doesn't drive so she gets concerned about that, that it's unfair on me and all that, but everything she does for me it's a small thing... I can rest up like I say to her if I know I've got to come out at 10.15, then I just rest and then come out... it's only half hour and then I can be in bed.

Jim It sounds like it's quite important for you to be able to do that for her...
Um... I want to have a contribution somewhere you know... she does so much for me a small thing like I said to do to [names location] and bring her back... err no she's good as gold.

CI So that's been something that's been really important in helping you get through by the sounds of it.
Jim Um like I said I wouldn't know how people do it on their own... I know you have to lower you're standards you know because you can't live like you did... you can't keep you garden up as you did before or your housework you know.

CI And have you been able to do that, that lowering of your standards?
Jim Yeah after a while... I say initially I was frustrated and want to throw things at the wall, 'cos I didn't understand it,

but now I do appreciate right, like I said to you I'm going to cut that hedge... it'll takes me all week but I'll do it 'cos I'll do a bit at a time and then I'll know that's it, you know I'll sometimes set the alarm on my phone for quarter of an hour or twenty minutes so it just tells me right you've done your twenty
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N C Chaloner
Research Dossier: Major Research Project

minutes because you can get carried away and then you pay for it later on it's not worth it and I like do little bits at a time.

CI What do you think led to that shift when you kind of went from throwing things against the wall and being really frustrated to being able to, to kind of...it sounds like you're adapting things around...

Jim I think acceptance of it and realising that this is it for me at the minute...I can't try and be the person I was two years ago and I'm not...I don't know if I ever will get back to that but it's getting it up in here [points to head] that this is what life is like at the moment...

CI Is there anything in particular that's kind of been important in helping that, you to kind of think OK this is how things are...

Jim It's not one thing...I think it's just time and the getting used to it and so the acceptance of it...I said to um [names facilitator] at the thing didn't I...I've got that thing on my notice board about thinking what you should be able to do and then thinking what you can do now in this situation but then only doing 75% of what you should do now, which leaves you that little bit of leeway you're not going to over-do it all the time um I say, reading bits and pieces has opened my eyes as well you know....I've read different books and it puts different ideas in your head about pacing you know and the meetings up with [names facilitator] you know she talked about that and it does all make sense um but it's making yourself do it when you've been so used to just getting up and doing what you want to do without thinking all of a sudden you've got to think like every step of the way otherwise it's like all of a sudden down again for two or three days...if you want to have some sort of quality of life it's just pacing yourself and accepting if I want to sleep I'll have to sleep whereas I'd get annoyed before...you know I've had enough sleep why do I not feel charged up, but you don't.

CI You talked a bit about going back to how you were before, how do you compare how you are now with how you were before...

Jim I feel I'm half the person I was before...

Jim Relating lowered goals to illness acceptance
    Linking acceptance to no longer trying to achieve the pre-illness self
    Questioning whether attainment of pre-illness self is possible
    Accepting current Circumstances

Jim Identifying multiple factors in acceptance
    Lowering expectations for activity
    Gaining new knowledge about managing symptoms
    Receiving knowledge through organised groups
    Difficulty following symptom management strategies
    Comparing current and pre-illness self; Recalling freedom of pre-illness self
    Being unable to act automatically; planning activity

Jim Comparing current/pre-illness self; Perceiving aspects of self as lost by
    Comparing current/pre-illness self; Perceiving aspects of true
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In what way, which bits have changed.

Jim

Oh it's the ability to be yourself.

I can only do certain things...I can't just go and do what I want to do I have to think about it all the time whereas before as I say I was quite sporty, kind of get up and go.

CI

Doing was quite important?

CI

Doing was quite important?

Jim

Oh yeah just normal going and having a beer with the lads, the boys always come over here every other week, they used to be in their boys football teams go and watch that um but towards the end, when I first got this my youngest boy was still doing football and I used to drive him there, but quite often I'd have to sit in the car and watch it whereas I used to get up and walk around and then I started talking a chair and folding chair in the thing, sit behind one of the goals and watch him from there, you can still, you can still um get involved but you have to do...

CI

Adapting things around...

Jim

Doing different things yeah.

CI

So you're finding different outlets almost for the same interests that you had before...

Jim

Yeah it's about having to adapt to do things slightly different um, you know I'm going shopping with [names partner] I always go food shopping with [names partner] and she pushes the trolley 'cos it tiring me out...it sounds pathetic doesn't it but that's what it's like, sometimes I think no I'll push it but I know I'll be knackered later or whatever words you want to use it is just a matter of thinking about it and changing you're ways a bit.

CI

We've talked a lot about kind of how things are now and I know you kind of talked a bit about the future earlier but I guess this sort of brings me onto the questions about where you see things going, where you feel you're going from hear...?

Jim

Well, like I say I'm getting married next week which is a step in the right direction but I'd also like to get back to working, some sort of work...even if it's only part time.

CI

What did you do before...

Jim

[names role and location] basically so I'd been there a long, long time I've got a lot of friends there and that's all sort of disappeared because it was always my sort of intention to work until I was 60, be able to retire on a reasonable pension and then go out and do some voluntary work or whatever, you know part-time work, but that's all been snatched away you know my pension has been frozen now until I'm 65...as I say it's only money isn't it, what was important is getting better, but I would like to go and do part time work but the problem is with this illness...I don't know when I'm going to get a good part on

illness.

Difficulty being 'true' self

Self as lost by illness

Being constrained by illness

Difficulty being 'true' self

Being constrained by illness

Difficulty undertaking pre-illness activities.

Linking difficulty being self to illness effect on constraining illness

Socialising with friends

Adapting activity to facilitate continued engagement with pre-illness activities

Difficulty following children's interests

Adapting activity to facilitate continued engagement with pre-illness activities

Adapting activities

Undermining post-illness activities

Pushing self beyond limits; awareness of 'costs of pushing self

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Adapting activities

Undermining post-illness activities

Pushing self beyond limits; awareness of 'costs of pushing self

Perceiving progress

Seeking a return to pre-illness role

Seeking a return to pre-illness life/role

Recalling pre-illness plans

Identifying pre-illness plans related to work

Perceiving pre-illness plans as inaccessible

Perceiving pre-illness pans as inaccessible

Emphasising importance of

Emphasising importance of
what day. I can’t guarantee to someone that I’m going to be able to work 10 till 2 or 12 till 2 whatever it is because it’s not like that so it puts you off even sort of offering to do things 'cos you let people down.

Emphasising importance of recovery
Seeking to engage in work
Plans hindered by shifting symptoms
Seeking to avoid letting others down

recovery
Plans hindered by shifting symptoms
Seeking to avoid letting others down

CI
Is letting people down something that you’d…

Jim
[interjects] yeah it’s not what I’d normally want to do um I don’t like it if people let me down and not being able to guarantee that plot of time you know why would someone want to employ me that can’t…

‘cos I wouldn’t want to employ someone that can’t guarantee they’re going to be their at certain hours, you just can’t.

CI
Have you got any kind of…have you had thoughts about what type of work you’d like to do…?

Jim
If I could get back to work, I’d like to do driving ‘cos I’ve had all those years in the office…’I’d like to be out and about bit of freedom you know um yeah I often look at the old van drivers when I’m out and about thinking yeah I wouldn’t mind being able to do that, but I know I can’t because I don’t know how to…no you can’t because I wouldn’t be able to lift the stuff for a start you know as it is, but that is my intention is to get back to work, I just don’t know when.

CI
Is that the main kind of goal.

Jim
Yeah we were even talking about fostering you know being foster parents um ‘cos both of us our children are more or less off our hands, my youngest is [names age] he actually lives with his mum but he comes here every other weekend type of thing, so we have actually looked at that um but the first Blake we went to recommended that we should be married.

CI
OK…

Jim
Um the didn’t…we ‘cos we’d said we were going to get married they thought well you ought to get that out the way first.

CI
Oh right OK…

Jim
Rather than trying start looking into fostering and going to training and all that when you’ve got this…and obviously I’d have to have a medical or something to see whether I was fit enough to be but we could always put [partner] as the main carer and I’d be the back up sort of thing, so that’s something we’re still looking at this morning funnily enough.

CI
Is that something that you, you would have thought about doing before or is that something…

Jim
Nah if I’d have still been at work I’d have just carried on as I say I’d have carried on in that job until I was 60 and [partner] works in a [gives profession] sort of situation um she [explains role] and obviously talking to her about…has opened my eyes ‘cos you don’t realise all that’s going on out there and we thought well
we're in quite a nice position to be able to do something about it we've got [X] bedrooms and only one gets used by [names son] when he comes over and there's a spare room there and we're both pretty easy going people and we just thought we could make a difference to somebody.

**CI** Is that something you feel you could do kind of at the moment?

**Jim** Well if [partner] was here as the main carer and I was just like the back up then yeah we probably could do it as a pair... it won't be easy we know that but that's part of the enjoyment of it or that's something that's hopefully in the pipeline.

**CI** Are there any other kind of things that come into your mind when you think about the future or any worries or fears?...

**Jim** I worry about money a little bit, I've got a bit of money at the moment because I was made redundant though the [names employer] to be fair to them didn't just kick me out the door which they could have done because I wasn't fit for work, but they sort of worded it that they were going to have a re-shuffle at my place of work which meant that my position would become redundant which means I've got a bit of money um but obviously that's not going to last forever.

**CI** And that's a concern....

**Jim** Yeah in the long term yeah... I keep thinking hopefully I'm going to be back at work by then... I've probably got enough money for a couple of years.

**CI** Do you think about those kind of things a lot or do you generally not think about them...

**Jim** Um occasionally it crosses my mind probably when bills come in you know and you see the money and your bank statement comes and you think well that can't last for ever.

**CI** What about more generally thinking about the future and planning ahead, is that something that you think about a lot or...

**Jim** I'm sorry, I can't sort of think too far ahead, it's more or less as you go day by day... it mind sound great to have two years off of work but it's not, you know people might think you haven't got to work for two years but it might be all right initially for the first few weeks but then it starts getting boring and driving you mad, it's not as if you're going off and doing what you want to do going on holidays, going and playing golf well you're not, you're trapped in your own little world, it's not much fun,

so I say looking to the future is like now really, where as before as I say I used to look towards 60, I was going to retire that was the plan before I got divorced it was like Oh when the children are older we'll have more time together in our 50's sort of thing then that was all snatched away and it was almost like back to square one again you know.

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<th>Wanting to make a positive impact on others</th>
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<td>Identifying shared plans with partner</td>
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<td>Experiencing financial worries</td>
<td>Worrying about money</td>
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<td>Seeking a return to work</td>
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<td>Perceiving financial resources as limited</td>
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<td>Being reminded of financial pressures</td>
<td>Difficulty contemplating the distant future</td>
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<td>Taking one day at a time</td>
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<td>Inability to undertake chosen activities; feeling trapped</td>
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<td>Recalling pre-illness future plans</td>
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<td>Being rooted in the present</td>
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CI What would it be like to think about those things all the time... the future?
Jim It would drive me mad I can’t afford to let myself think... I don’t know what I’m going to be like in six months time, a year’s time, hopefully I will be better so to speak, but as it’s been going lately you know I don’t feel like it nah... long term things have sort of gone out of reach really.

CI Is there anything else about how you see yourself now or how you think about the future?... I mean what is it like even to be asked about those things?
Jim I don’t mind but it’s just difficult to explain it the future is tomorrow or the rest of the day and then tomorrow yeah ‘cos everything I do I have to sort of plan even you know what I’m going to do tomorrow I have to think about it ‘cos tomorrow I’ve got to meet [partner in town] and look for a wedding [indecipherable] so that will have to be sort of thought about you know she’ll be starting work at 3, half 2/3 so I’ll meet her at 1 which gives us an hour and a bit or something which means I don’t have to get up so early you know um whichever, anything you want to do you know you’ve got to think about it all the time.

CI Are there any times when you find yourself thinking more about plans or the future than others or is it always kind of a little bit...
Jim It’s always bubbling away there, yeah you see people carrying on their lives and that and you get a little bit that you want to be like that and you know people paying for their holidays and you can’t be doing that and that sort of side if it’s taken away from you a little bit um some... [tape cuts out to turn over] it’s just too much a lot of it my mates of that age they’re all there [referring to a wedding] and then you’re missing out on or you feel like you’re missing out on bits like that.

CI Do you feel like that a lot that you’re missing out on things?
Jim Yeah, you’re not part of what you should be or what you were before it’s almost sort of not cast aside but you’re away from it at the moment you can’t get back to it... you know you keep being invited to different things but you can’t actually...

CI Would you want to go to those things?
Jim I always would have done yeah ah we’ve known each other since school age like that I say we grew up playing football together and now we play golf together or we did and er that’s all just a knock on from it you know people’s birthdays and you go out for a meal whatever and you’re not able to join in with it all and I accept it more that I can’t do that so it’s stupid me trying to do it where as in the early days perhaps I would have tried and then knocked myself out you know, but I’ve realised now that it’s

Starting over
Avoiding thoughts of the future
Difficulty predicting future
Hoping for recovery
Uncertainty regarding recovery
Perceiving long-term goals as inaccessible; beyond control

Managing distress by avoiding thoughts of the future
Perceiving long-term goals as inaccessible

Difficulty thinking ahead/being rooted in the present
Reliance on short term plans
Providing examples of short-term plans

Planning day according to demands
Engaging in continuous planning

Comparing self to others; Envyimg others
Perceiving others lifestyles as inaccessible

Missing out on social activities
Feeling separated from pre-illness existence
Inability to fulfill social engagements

Recalling long-standing friendships
Difficulty engaging in pre-illness social activities

Difficulty engaging in pre-illness social activities
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<thead>
<tr>
<th>CI</th>
<th>Do you feel that you’ve um changed in any way since having CFS?</th>
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<tbody>
<tr>
<td>Jim</td>
<td>Um...I think I changed a bit after my divorce you know, I think things that were important to me became unimportant like football you know, getting wound up if your football team lost, what’s the point of that, you know there’s more important things all that and er a good friend of mine as well they [gives details of his friend’s bereavement] and that sort of opens you up, you know I’m meaning about my situation and then you get hit with that um and [goes on to give details about bereavement] so those sort of things hit home to you and you think what am I you know, I’m inconvenienced by this but it’s not going to kill me... hopefully.</td>
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<thead>
<tr>
<th>CI</th>
<th>Is there anything that you value more now or that you’ve grown to value more since having...</th>
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<tbody>
<tr>
<td>Jim</td>
<td>Well my close friends, I’ve realised who my close friends are um even within my family and the ones that are there for me and the ones that haven’t been you know, they would be if I’d open up I’m not saying that there’s nothing coming back the other way like there is with one or two of them...yeah so it’s opened my eyes in that way a little bit.</td>
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<tr>
<th>CI</th>
<th>Anything else.</th>
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<tbody>
<tr>
<td>Jim</td>
<td>I’ve always been pretty easy going anyway, pretty laid back like I say I don’t like change very much um...I was initially disappointed about losing my job and all that but I’ve accepted that pretty much but if I’d stayed there I’d have probably had to try and move to something slightly different because I wasn’t enjoying...I was feeling the pressure of what was coming on you know it’s the same old thing people were retiring and they weren’t being replaced everyone else was expected to take a bit more and a bit more...er...I don’t know I suppose you’d have to ask other people if they think I’ve changed.</td>
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<tr>
<th>CI</th>
<th>Ok what do you think [partner] would say...?</th>
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<tbody>
<tr>
<td>Jim</td>
<td>Um...I don’t know really, I’m trying to think what someone else would...as I say she notices if I stop talking the tablets and I get a bit touchy ‘cos I’m not normally like that, we’re both pretty quiet um...I’ve become interested in other things like the bird watching.</td>
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<tr>
<th>CI</th>
<th>Yes...</th>
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<tr>
<td>Jim</td>
<td>And there’s bits like that that I’ve got out of it, I’m um a member of the [names organisation] as well so I get their books coming through.</td>
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<tr>
<th>Accepting changes in social activities</th>
<th>Accepting changes in social roles</th>
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<tr>
<td>Adjusting nature of social contacts</td>
<td>Linking self-change to pre-illness stressors/events</td>
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<tr>
<td>Accepting illness related losses</td>
<td>Accepting illness related losses</td>
</tr>
<tr>
<td>Considering others appraisal of self</td>
<td>Difficulty identifying others perceptions of self</td>
</tr>
<tr>
<td>Developing new interests post-illness</td>
<td>Developing new interests post-illness</td>
</tr>
</tbody>
</table>
And is that a new interest?

Yeah, it’s cos I’ve had the time to be able to just sit as I say it’s interesting when you get the different birds coming in like the woodpeckers and things so it’s quite nice to see that, yeah but um I don’t watch a great deal of telly either... I used to watch the football but I can’t be bothered with it anymore it doesn’t seem that important and I get annoyed anyway when I... it’s all hyped up you know the amount of money they get paid you know it just turns me off er I’d rather watch the golf.

Is there anything else that you haven’t talked about that you think would be helpful for me to kind of know about or to try and understand?

I think you understand that the main thing is the frustration of this condition, the not knowing how long you’re going to have it for... like I said before if they said you’re going to have it for the rest of your life you could perhaps deal with it and say right this is it...I’m not going to get better um it’s a horrible, horrible disease that’s all I can... well I don’t know if it’s a disease or a condition...

It’s so unknown..

Just a debilitating, frustrating time, I had as I say at Christmas time, I had picked up again and I was thinking to myself perhaps this is the start of... and people were telling me again um I was walking better and even [partner] said you’re walking faster um which is something I hadn’t really noticed and I said oh that’s good but now it’s all sort of gone backwards again which is er disappointing and then people say to you well there is hope perhaps you will... this just a relapse and they try say all the right things.

Does the peaks make it any easier or do they... going through that period where things seem to be getting better does that make it any easier??

It’s disappointed me so much in the last 2 or 3 weeks where I’ve felt so rough you know I thought I’d gone past that and I was starting to feel a little bit more like it you know, not ever doing it but just feeling a little bit better and er that’s all just sort of crashed down again, there’s nothing there... I ache like I’ve got the flu all the time, that’s what people don’t see and my neck aches all the time and if I walk up the stairs it’s like when you’ve got flu in you’re legs that’s what it’s like but people don’t see that, they just see the outside... yeah so it was nice to feel a little bit brighter at the time um just disappointed that it’s gone back the other way... you’ve got to live in hope.

Is that important hanging onto that hope?

Well something’s got to happen with it hopefully, you know, I think it is unusual for people to have to for a long, long time and saying being a member of... you do talk to people that is recovering no a friend...
of mine brought his new girlfriend round and she had it for 10 years but when she came round here you’d never ever no and she had it from her mid 20’s to mid 30’s but now she’s running round like a 2 year old trying to make up for lost time.

CI Does seeing those people who’ve kind of gone through it and come out the other side is that something that helps you?

Jim Yeah oh yeah it gives you hope that I’m going to be one of those, fingers crossed and um because I want to be as well like the doctor said at the hospital you know you do want to beat it so I think you will. You know you don’t want to be like this for the rest of your life ‘cos it’s no fun.

CI Does having professionals saying you know you want to get better so you will what’s...

Jim Well it’s encouraging.

Jim It’s encouraging.

Jim Yeah I don’t think I’ve wasted my effort trying to think positive and I went to a speech down at [names venue] given by [names speaker] and it was a bit complicated what he was talking about but you know you did understand it in the end and er I bought some tablets these veggie PA tablets which are um virgin evening primrose oil and I’ve been taking them since then and that was like Nov/December time ‘cos I used to have a foggie head as well and that’s cleared um it’s almost like having a hangover all the time and that was horrible but that’s clear now which means I can read a bit more and I can watch a bit more telly without my mind wandering off and wanting to fall asleep all day, um so that’s been a step forward and that sort of coincided with the time I was feeling a bit better and um well I was just fooling myself ‘cos I’d cleared the head and I was thinking I was feeling brighter and now it’s all, I’ve realised I’m not quite there...

No it’s nice to be told that you are thinking positive and you’re not gonna and just role over ‘cos there’s one or two people at [names facilitator’s] thing and you think blimey you’ve gotta do a bit for yourself you know with the way they’re talking you think blimey you’ve gotta... I’m not as bad as that am I... I hope I’m not coming across like that. You see the ways different people are coping... I wish I could remember how I ended up there.

CI Don’t worry, I’m conscious of the time and that I’ve kept you quite a while, I just wanted to give you the opportunity if there was anything else you wanted to say to say it um but I don’t want to draw things out too long if you’re...

Jim I’m fine if you’ve got anything else you’ve got to ask.

CI No I haven’t got anything else I have to ask but if you wanted to... um

Jim No.

Meeting recovered individuals

Gaining hope from others

Others seeing recovery as dependent upon attitude/choice

Justifying the unwanted nature of illness

Justifying efforts to remain positive

Attending professional speeches on illness experience

Difficulty understanding professionals

Undertaking complementary treatments

Perceiving complementary therapies as beneficial

Experiencing improvement in cognitive symptoms

Improved ability to concentrate

Experiencing progress

Perceiving improvements as false

Valuing confirmation of positive attitude

Valuing confirmation of positive attitude

Others seeing recovery as dependent upon attitude/choice

Justifying illness as unwanted

Perceiving complementary therapies as beneficial
APPENDIX 9

(Major Categories and Corresponding Sub-ordinate Categories)
Table 3: *Subcategories and Focussed Codes Comprising Major Categories*

<table>
<thead>
<tr>
<th>Major Category</th>
<th>Sub Categories</th>
<th>Further Sub Categories</th>
</tr>
</thead>
<tbody>
<tr>
<td>BECOMING UNWELL</td>
<td>EXPERIENCING MULTIPLE SYMPTOMS</td>
<td>SHIFTING SYMPTOMS</td>
</tr>
<tr>
<td></td>
<td>ILLNESS DISRUPTING ACTIVITY</td>
<td>SHIFTING CAPACITY TO ENGAGE IN ACTIVITY</td>
</tr>
<tr>
<td></td>
<td>EXPERIENCING UNCERTAINTY</td>
<td>PAYING AN UNCERTAIN PRICE FOR ACTIVITY</td>
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<tr>
<td></td>
<td>(UNCERTAINTY SURROUNDING ILLNESS ONSET/CAUSE; AMBIGUITY SURROUNDING ILLNESS PROGNOSIS; EXPERIENCING SYMPTOMATIC UNCERTAINTY)</td>
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<tr>
<td></td>
<td>EXPERIENCING CHANGED RELATIONSHIPS</td>
<td></td>
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<tr>
<td></td>
<td>(ILLNESS IMPINGING ON THE LIVES OF OTHERS)</td>
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<tr>
<td>CFS AS A CHALLENGE TO IDENTITY</td>
<td>LOSS (EXPERIENCING A LOSS OF SELF)</td>
<td></td>
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<tr>
<td></td>
<td>CONFUSION (ILLNESS MASKING TRUE SELF)</td>
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<tr>
<td></td>
<td>CONFLICT (BEING CONSTRAINED BY ILLNESS</td>
<td></td>
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<tr>
<td></td>
<td>CONSTRUCTION OF THE PRE-ILLNESS SELF;</td>
<td></td>
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<tr>
<td></td>
<td>ENACTMENT OF PRE-ILLNESS SELF HINDERED BY ILLNESS; NEGATIVE CONSEQUENCES OF SELF-ILLNESS CHANGE</td>
<td></td>
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<tr>
<td>MAKING SENSE OF ILLNESS</td>
<td>QUESTIONING ILLNESS VALIDITY (NOT QUESTIONING ILLNESS VALIDITY)</td>
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<tr>
<td></td>
<td>QUESTIONING AGENCY (NOT QUESTIONING AGENCY)</td>
<td></td>
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<tr>
<td></td>
<td>FEELING MISUNDERSTOOD (FEELING DISBELIEVED; JUSTIFYING ILLNESS)</td>
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Contemplating the Future in CFS: A Grounded Theory Exploration of the Experience of Self and Contemplation of the Future Across Individuals with Chronic Fatigue Syndrome
<table>
<thead>
<tr>
<th>NEGOTIATING RESPONSES</th>
<th>DISTANCING</th>
<th>INTEGRATION</th>
</tr>
</thead>
<tbody>
<tr>
<td>(Resisting self-illness changes; Containing illness)</td>
<td>(Accommodating illness within pre-illness activities; Developing new roles/interests compatible with illness)</td>
<td></td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th>WILLINGNESS TO CONTEMPLATE THE FUTURE</th>
<th>DIFFICULTY CONTEMPLATING THE FUTURE</th>
<th>DISTRESSING LIMITS; Undermining current progress; Separating self from illness Controlling emotions associated with illness Adjusting expectations; Pacing; Identifying positive self illness changes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Conflict between current existence and future plans (Influence of developmental stage; Presence/Absence of illness in the future)</td>
<td>Illness as temporary (Seeing fulfilment of plans as dependent upon recovery) Integrating illness within the future</td>
<td></td>
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<tr>
<td>Considering alternative futures (Fluctuating symptoms/periods of improvement fostering hopes of recovery)</td>
<td>Being stationary (Living in the present; Taking one day at a time; Being task focussed) Waiting for recovery (Battling to keep hope alive)</td>
<td></td>
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Contemplating the Future in CFS: A Grounded Theory Exploration of the Experience of Self and Contemplation of the Future Across Individuals with Chronic Fatigue Syndrome
APPENDIX 10

(Quotations Corresponding to the Major Category of: Becoming Unwell)
Becoming Unwell: Associated categories, sub-categories and selected quotes:

<table>
<thead>
<tr>
<th>SUB-CATEGORIES</th>
<th>SUPPORTING QUOTES</th>
</tr>
</thead>
<tbody>
<tr>
<td>Experiencing, varied multiple symptoms</td>
<td>Margaret: I couldn’t get out of bed and I was ill.</td>
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<td></td>
<td>Margaret: I’ve got problems with, you know, concentrating on my work, you know.</td>
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<td></td>
<td>Margaret: Um, I couldn’t concentrate.</td>
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<td></td>
<td>Margaret: Weeks of just lying in bed every day.</td>
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<td></td>
<td>Margaret: I have terrific trouble with sleep, tremendous trouble with sleep um.</td>
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<td></td>
<td>Margaret: Part of it is the mental fogginess and it’s literally like having cotton wool in your brain.</td>
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<td></td>
<td>Emily: I lost all my energy and then had all the really typical sore glands, sore muscles, nerve pains, just general aches no energy um poor concentration, poor memory all the cognitive stuff went completely down hill.</td>
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<td></td>
<td>Emily: But one of the really big things is that if there’s the slightest bit of stress it will immediately trigger anxiety and it will be like this um it’s not the, the normal stress reaction it will trigger something to just keep, the stress reaction just going and going and going and get worse and worse and worse.</td>
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<td></td>
<td>Emily: Ok, um it started off with just um me feeling sort of dizzy and faint.</td>
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<td></td>
<td>Lucy: I had pain as well in my arms so I was getting pain, I’d wake up in the morning and I couldn’t sort of do this [flexes arms at the elbows] open up my arms properly um so... so that’s what it was like.</td>
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<td></td>
<td>Lucy: There’s always something there fatigue or dizziness and the nausea, I get quite bad nausea with the dizziness as well.</td>
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<td></td>
<td>Lucy: My balance was poor and I was struggling to you know walk.</td>
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<td></td>
<td>Lucy: And I had the most dreadful headache and I just found it very difficult to walk and it was like I was walking through treacle.</td>
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<td></td>
<td>Lucy: And I just had this continuous fatigue, you know palpitations because like I’d been running or something.</td>
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<td></td>
<td>Lucy: I get quite a lot of feeling like fluey symptoms and my glands come up and maybe a sore throat.</td>
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<td></td>
<td>Rose: And er I’m very light sensitive and noise sensitive.</td>
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<td></td>
<td>Rose: I was having great difficulty with walking at the time.</td>
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<tr>
<td></td>
<td>Peter: You know my brain was hurting the tinnitus was there there’s nearly always a headache.</td>
</tr>
<tr>
<td>Illness disrupting activity</td>
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<tr>
<td><strong>Peter</strong>: I was falling asleep about eight times a day at work.</td>
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<tr>
<td><strong>Jim</strong>: I feel like I’ve got that much energy [moves index finger and thumb a small distance apart].</td>
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<tr>
<td><strong>Jim</strong>: I mean I sleep 14-16 hours a day.</td>
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<tr>
<td><strong>Jim</strong>: I ache like I've got the flu all the time, that's what people don't see and my neck aches all the time and if I walk up the stairs it's like when you've got flu in you're legs.</td>
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<tr>
<td><strong>Sam</strong>: I got worse again, tired and I got all the physical symptoms back as well, like muscles, I get bad muscles and I get very tired.</td>
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<tr>
<td><strong>Sam</strong>: And I know the physical symptoms I get tingling in my hands as well and stuff like that.</td>
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<tr>
<td><strong>Sam</strong>: I've got a sore throat and my glands hurt.</td>
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<tr>
<td><strong>Margaret</strong>: Physically, well I was physically active but I would come home and I would collapse.</td>
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<tr>
<td><strong>Margaret</strong>: Well you get to 4 or 5 O'clock in the afternoon, you feel like a nap, that's just when dinner is starting to be needing to be getting ready.</td>
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<tr>
<td><strong>Margaret</strong>: I wasn’t fantastically physically active, although I should say Tai-Quando is a very high energy sport and I would come back and I'd sit on the sofa and I'd go phwoop [moves as if to collapse on sofa] and I'd be out.</td>
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<tr>
<td><strong>Emily</strong>: Being this sudden um really debilitating anxiety problem which actually stopped me doing my A levels half way through.</td>
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<td><strong>Emily</strong>: Having to pull out of things at the last minute.</td>
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<tr>
<td><strong>Emily</strong>: That's what I find, that may just be my case but I find that I'm wanting to do things before I can actually do them um.. physically.</td>
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<tr>
<td><strong>Emily</strong>: I've already tried to go to University, after week five, I had to come home because I got fresher's flu and two other viruses at the same time.</td>
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<tr>
<td><strong>Peter</strong>: I found I couldn't read um I used to read books, you know go to bed and read a chapter um I got to the stage where I couldn’t absorb anything because the brain started hurting and the eyes started hurting.</td>
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<tr>
<td><strong>Peter</strong>: And all the coastal paths um but I did three of those and found that I just couldn’t handle it.</td>
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<tr>
<td><strong>Peter</strong>: Because I don’t have the energy to, to want to do anything.</td>
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</table>
| **Peter**: I’d love to go out for the walks that the [names social group] do um I started line dancing, I mean two years ago, because I wanted to try things and do things um and I love dancing and line dancing I think it’s...
fantastic um but the brain wasn’t working and my feet after an hour and a half of line dancing was like a ten mile walk um.

**Peter:** I get the vacuum cleaner out with good intentions I mean it’s behind the settee at the moment and I think I got it out three weeks ago um it just doesn’t happen.

**Rose:** It won’t let me concentrate enough to do my Tesco online shop and it won’t stay quiet long enough for me to rest properly.

**Rose:** You know going to the shops and falling apart um because it was so difficult to walk and I would go into a café and sit and have a drink and think oh I’ve had a rest I’ll be alright now but it was you know, really hard to get back to the car again.

**Rose:** I usually find it hard to eat my dinner because I’m so tired and having cooked it it’s hard to sit at the table and then um after dinner the family know they won’t get any sense out of me because I can’t, can’t think enough to converse and string sentences together.

**Rose:** We had 7 lessons, 8 lessons this term and I’ve only managed to get to three.

**Jim:** The other thing I do is rest a lot and sleep a lot, I don’t see the mornings very much at all.

**Jim:** I don’t know if I’ve just done something some menial sort of task and it’s drained me.

**Sam:** I like reading but sometimes when I’m really tired, I can read a magazine that I can just pick up and put down and flick through but I can’t sometimes read a book that I have to concentrate on um so I think that’s another kind of problem...sometimes I’m just too tired to do it.

### Experiencing Uncertainty

**Uncertainty surrounding illness onset/cause**

**Emily:** And you just don’t understand why it’s happened either.

**Emily:** I would have been just changing school, so probably added stress of moving from middle school to secondary school probably made it all worse, um I don’t know if this is anything to do with it but actually before I had the glandular fever, one thing that I did notice was that whenever I used to do loads of athletics and just be one of those annoying kids who if there’s one way of getting from A to B, they’d never take the easy way they’d always bounce or jump or hop [laughs] and um and I noticed that when I was doing the 200 metres at school I’d absolutely always throw up after, immediately afterwards and so that’s just in the back of my mind and in the back of my parents mind, we always wondered whether that was the beginning of it.

**Lucy:** Because you can’t take medication for it, because there is no real understanding as to why it really happens.

*Contemplating the Future in CFS: A Grounded Theory Exploration of the Experience of Self and Contemplation of the Future Across Individuals with Chronic Fatigue Syndrome*
Jim: Um oh I can’t I remember how it came about it was obviously in the early stages I went to my GP and had well I didn’t understand what was going on with me at the time and nor did they basically I mean they tested me for all sorts of things um polymyalgia, fibromyalgia all this.. glandular fever and all this blood tests and when they all come negative.

Jim: Well I don’t know if it’s a disease or a condition.

Jim: Well I first it’s two years now but I first had symptoms in [names date over 2 years ago] when I was playing golf I felt something not quite right ‘cos I played a lot of golf towards the end of it and I was feeling absolutely shattered and I never recovered really since then.

Jim: They said initially they diagnosed depression which scared me a bit because I’ve been depressed before over a divorce and I didn’t want that, you know. But anyway I was then thinking of all sorts of things that were wrong with me you know as you would and then when I was diagnosed with Chronic Fatigue.

Peter: And the doctor said well it’s probably emotional comeback and see me in six months time and in six months it was still happening. I went to see a neurologist up in [names location] and um they diagnosed...the doctor had already said it was probably [gives diagnosis] um and he put me onto amphetamines and forgot me um and then er I passed out in I passed out here when my son was here about 10 years ago and they put me through some tests...I ended up in [names hospital] with wires attached to my head um and it proved that I have a problem but it wasn’t [gives previous diagnosis], I didn’t fit into all the boxes.

Peter: That I’ve noticed things, I remember things, I mean I had a reputation when we used to go camping with [names group] I mean if it was a nice day and we’d had our lunch and everyone had to be quiet in their tents for half an hour I’d, I’d lay on the bench tables in the sun and go to sleep um to me it was a natural thing to do but people don’t do that necessarily at my age then um and so a number of flashbacks meetings I’d had in the past as a [names profession] I can remember not actually falling asleep but my mind disappearing for a very, very short time um and I suppose it just, it just, projecting the thinking made me wonder if I was the reason for the divorce.

Margaret: So you can treat the symptoms basically get rid of that viral load, which he managed to do, he managed to get me virtually back down to a normal viral load but, and nobody knows why, it can come back.

Emily: If you think back how many times has it happened then the more times it has happened you think the more times it’s probably going to happen.

Jim:... the not knowing how long you’re going to have it for.

Jim: [interjects] it can be but it’s also a frustration, it’s like having a prison sentence and not knowing how long you’ve got.

Jim: And you know I do meet people that have recovered from it because I’m a member of [names group] and that’s got quite a few people in there that are not fully recovered but 90%,they can live sort of
Experiencing symptomatic uncertainty

Shifting symptoms

Jim: How long am I going to be stuck like this for ‘cos I don’t think, there’s no sort of average time, it’s an individual, you know it could be one year it could be 20 years um.

Jim: I think you understand that the main thing is the frustration of this condition, the not knowing how long you’re going to have it for.

Sam: OK, well, when I was at University so it was about probably 8 or 9 years ago I got glandular fever um...it took a long time to actually diagnose because um the GP down there was just kind of dismissive “oh, it’s a virus, it’s a virus” but I didn’t get better and so I went...so it kind of took a look time to actually, actually find out that it was glandular fever so of course I was just trying to carry on as normal um, which probably made things a lot worse and so I just couldn’t get better and ended up having to go home and had to have a year off University um so during that time obviously in hindsight I can kind of tell you know why.

Sam: But there’s nothing ..you know I’ve been to the doctors there’s nothing wrong and there never is [laughs].

Margaret: the thing about it is that I do have clear days, days when I wake up and my brain doesn’t feel fuzzy, but they’re very few and far between [pauses].

Emily: Yeah because like a lot of people say with CFS you definitely do have up days and down days and you can never tell when they are going to come because it seems to just be random as far as I can tell.

Jim: I can watch a bit more telly without my mind wandering off and wanting to fall asleep all day, um so that’s been a step forward and that sort of coincided with the time I was feeling a bit better and um well I was just fooling myself ‘cos I’d cleared the head and I was thinking I was feeling brighter and now it’s all, I’ve realised I’m not quite there.

Jim: Because you never know how I’m going to feel but um.

Jim: Because I don’t know how I’m going to feel.

Jim: I don’t know when I’m going to get a good part on what day.

Jim: It’s disappointed me so much in the last 2 or 3 weeks where I’ve felt so rough you know I thought I’d gone past that and I was starting to feel a little bit more like it you know, not over doing it but just feeling a little bit better and er that’s all just sought of crashed down again, there’s nothing there.

Rose: Then of course it caves in again, it never lasts longer than maybe two weeks if I’m lucky. [Talking about short-lived good times].
**Shifting capacity to engage in activity**

**Emily:** And you can just wake up one morning and you know that you’re just going to be a blob for that day and you’re not going to be able to do any of the things that you had planned.

**Emily:** You can just wake up one morning and you know that you’re just going to be a blob for that day and you’re not going to be able to do any of the things that you had planned...the things that you need to do such as if you’re independent um you might need to be doing you’re shopping or whatever.

**Lucy:** So it depends I, I can get up at say 8/9 O’clock in the morning, get dressed or something, have a cup of tea, but then I feel tired, I feel tired so I’ll sit down probably for a little while and then I’ll get up and I’ll do something else mainly just to break the sheer boredom really and um I might, depending on how I feel, I might go for a very short walk, um but I know my limitations so it varies it could be a very short walk to halfway up the road and back that might be all [indecipherable] I can do um but then I’ll come back and I will feel, tired, afterwards, and that sort of varies as well.

**Rose:** that I can do like on a good day now I can manage half a day in the garden, you know sort of sitting down, weeding jobs those kind of things and at the end of the half an hour I can look at the bit I’ve done and I get a sense of achievement from that so little things.

**Rose:** Well it’s very difficult to describe a ‘typical’ day because they are all so different, you know, you can have a day when you can’t do anything and it’s spent either in bed or on the sofa which is what most of last week was or you can have other days when you feel more active, more able to do things.

**Rose:** To have done something in the evening then I know I can’t arrange to do something the next morning because I might be in bed all the next morning ‘cos I’m a wreck from the evening before so it’s, it’s all a sort of juggling act all the time.

**Margaret:** And knowing that if I push myself today, it isn’t going to effect me for the next two days or even three.

**Emily:** And there’s just no way that I can do that. If I do something like that either I’d get semi comatose halfway through or after I’ve done it, I can’t do anything for a week or two. So just doing any sort of physical or mental or physical activity. There’s always a pay back. Either you’re physically not well enough to do it at the time because you don’t have the energy there...or you can do something if it’s small enough and you sure know about it later that day or the next day and for a week to come.

**Emily:** Yeah um just reigning yourself in all the time because you know that there is going to be a pay back, maybe over a really large number of years.

**Lucy:** When you spend you might have say two awful weeks you might have a good day, you might not be able to help yourself, you might say over do it even though it’s not that you’re overdoing it and pay for it for,
you know however many days or weeks and it’s so.

Rose: To have done something in the evening then I know I can’t arrange to do something the next morning because I might be in bed all the next morning.

Rose: Because that’s when you are likely to crash for several days afterwards.

Jim: I have to be so careful because if I overdo it, it knocks me out for 2 or three days it just flattens me and I can’t do anything at all.

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**Experiencing changed relationships**

Emily: You’re just feeling so unwell that there’s no two ways about you going out.

Emily: As soon as I got ill and as soon as I couldn’t go out and do things with them, they dropped me um which is a huge thing and I still notice me thinking in ways um that are less than trusting because of them having done that to me.

Emily: ...Er but I’ve also been disappointed with people that you think would come and visit you or at least phone you and they don’t and I sort of think to myself if it was the other way round I’m sure I’d be in touch with you a bit more you know, people that you think are your quite close friends...yeah I’ve got one my best mate he phones me every week and he’ll come over every two or three weeks to come and see me but then there’s other people that you know, blimey it’s been two years and I’ve had one visit from one of the chaps and it disappoints you.

Lucy: Don’t really have a social life.

Lucy: I think a lot of things that I did before I was ill have obviously changed now um my relationship, my partner, my friendships um just the everyday things that I used to do really you know, shopping, cooking going out, going to the cinema, you know things that we all do.

Lucy: Um that’s partly, partly probably the reason my relationship broke down, partly because he couldn’t cope with my illness. I found social situations difficult and he found that difficult my not being there.

Lucy: Um, I think actually earlier on it was really hard, earlier on it was really hard because um I, I still talk to some of my colleagues at work and it, I think I, I wouldn’t say I was jealous but it was, I felt really left out I don’t know, they were doing all the things the things that I wasn’t doing but still wanted to do.

Jim: It’s just too much a lot of it my mates of that age they’re all there (referring to a wedding) and then you’re missing out on or you feel like you’re missing out on bits like that.

Jim: I always would have done yeah ah we’ve known each other since school age like that like I say we grew up playing football together and now we play golf together or we did and er that’s all just a knock on from it you know people’s birthdays and you go out for a meal whatever and you’re not able to join in with it all and I accept it more that I can’t do
that so it's stupid me trying to do it.

Jim: It just made it worse I mean emotionally, it just made it so much worse really, because you think well you know, these people, they're supposed to be my friends and they're supposed to be my partner and I just, I don't know if it just made me feel so lonely and it made me feel like I didn't, I couldn't, they couldn't relate to me and although I understood their lifestyle I couldn't participate in it, I wasn't able to do it.

Rose: And I was so tired, I felt awful and I couldn't cope with the noise in the restaurant and my elder daughter was sitting opposite me and I was just so aware of being such rotten company because I couldn't think what I was talking about, I couldn't think of a new topic of conversation, I wasn't following what she was saying.

Rose: Yesterday, um a friend that I was at college with um we got in touch with each other in [date] and that was like 25, 30 years whatever since we'd seen each other and we had a wonderful chat on the phone, really got on well and err, she said she was coming to this area the following week and we must get together for lunch and she said she'd ring me whenever she knew what her schedule was and she happened to mention that she was having to cover for a colleague who had ME and it was you know such a nuisance and I stopped the conversation by saying well actually, I have ME and she said "Oh right, right, well I must go know" and the conversation finished and the phone call to have lunch never happened and I never heard anything more from her.

Rose: And she said oh we must get together one weekend and then er she said, "oh you said in your email you apologise for replying late but um you'd had a bad week last week, have you not been well or something?" so I said oh it's just the ME It's an ongoing thing which is all I said, and she said "Oh, right well I've got to go now" and I just couldn't believe it I felt so crushed, I really felt crushed she obviously thought, well she wanted nothing to do with me.

Sam: But I've got I had one friend who was my best friend for years and she wasn't very supportive when I was ill um which did bother me in the fact that I was sat at home for 8 months by myself and she was an [names profession] so used to have you know three days of the week off at home and she never once popped on and I could have done with you know some company [becomes tearful] but I didn't say anything.

Margaret: But my husband I think feels frustrated because he knows that I need to limit how much I do, but the more I limit, the more pressure it puts on him to do those things that have to be done and so he feels that.

Margaret: And also I don't have a job so that means that you know that he's also the complete breadwinner and that's a sort of pressure on him and he's under tremendous pressure at the [names place where husband works].

Emily: Yeah there is a huge amount of insecurity and also guilt that goes along with being long term ill because you also feel guilty that you're either you're sponging off society or in my case I'm putting my parents through hell.
Lucy: And I also feel for my family because I was in a relationship for a while and that broke down, you know that broke down last not last year, [gives date] so I had to move in with my parents so that was hard.

Lucy: Not having my job, I just thought I didn’t want to lose my job I don’t want to and I spent you know, I didn’t want to let anyone down, I was just so worried because I’ve let them down and haven’t been to work.

Rose: We'd had to cancel once before because I was ill and I was so tired I really didn’t feel up to going but I thought I can’t cancel it again and let everybody down.

Rose: I thought, I'd looked forward to that so much and it seemed like such a missed opportunity because if I’d seen her another day or maybe earlier that day, or probably not that day because I wasn’t feeling that good, but any other day or time we could have had a wonderful chat.

Rose: Well there’s still an awful lot of guilt because it impinges so much on the lives of the people around me you know my husband's life is constrained by me.

Rose: He can’t do what he wants to do on holiday.

Rose: I’m a wreck and that’s cooking a simple meal so we now try to work on the idea of maybe him learning to cook so that maybe he can cook and I can talk but you know I'm aware that that’s constraining his life.

Rose: Umm yes I hate, hate, hate asking favours unless I know that I can pay them back in a particular way I don’t want to build up a deficit because it’s not fair on other people.

Rose: But also I felt the awkwardness and embarrassment of having to email her and say well actually I've thought about it and I don’t think it’s feasible and she was very kind about it and you know she, she understood, thankfully, but it was just another one of those times when I felt like I’d let other people down by you know thinking something was possible and then realising it wasn’t possible.

Rose: I think it probably is, yeah, yeah, I think it probably is, I just wish I could compartmentalise this so it didn’t impinge on other people, you know, that’s, that’s the frustrating bit.

Jim: Um, I want to have a contribution somewhere you know she does so much for me.

Jim: I’ve got a partner who goes to work full time and she comes home here and tries to do the house work you know everything you just feel a bit like er on a loose whatever, you know you can’t contribute as you would like to.

Peter: So it was a, a physical and mental challenge um and then when you’re there they’re out at work it’s like all visitors most children are out at work nowadays so when you go and visit someone you’re by yourself during the day and I don’t think that they appreciated, they realised that I’d stopped going because I was unwell and they are very busy so but
now I'm in the situation that I don't keep asking myself what would happen if they telephoned or ring the front door bell...I just don't want to see them because I can't handle it.

Sam: I think at the moment I'm quite by myself and [names partner] is the only person who is really, really supportive which is kind of quite a burden on him I think at the moment but.

Sam: It must be a bit because he's the one that...every time I kind of want to chat about anything it's always him, I haven't got you know, there's not many people to spread it out between.

Peter: You know I'm very lucky I can become a slob and it doesn't affect anyone except me.
APPENDIX 11

(Quotations Corresponding to the Major Category of: Experiencing a Challenge to Identity)
CFS as a Challenge to Identity: Associated categories, sub-categories and selected quotes:

<table>
<thead>
<tr>
<th>SUB-CATEGORIES</th>
<th>SUPPORTING QUOTES</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Loss</strong></td>
<td>Margaret: At that time it was like my personality disappeared.</td>
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<td></td>
<td>Margaret: Um, the only way to explain it is to say that, you lose yourself.</td>
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<td></td>
<td>Margaret: It feels, it’s almost like it feels like you lost yourself.</td>
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<td></td>
<td>Emily: And at the moment I get just sudden huge feelings of grief for the life that I’ve lost.</td>
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<td></td>
<td>Jim: I feel I’m half the person I was before.</td>
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<tr>
<td><strong>Confusion</strong></td>
<td>Emily: A big part of the difficulty is knowing what part of a) your personality and b) your reactions to things are because of CFS or are because of growing up.</td>
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<td></td>
<td>Emily: I don’t know if it’s me being a teenager or if it’s me having CFS. So you don’t know which, in a way you regard CFS as being a false layer on top of everything and that it’s difficult to know what genuine changes.</td>
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<td></td>
<td>Lucy: Probably yes, I suppose, I can’t really pinpoint it though I can’t really, I suppose, I don’t know I can’t pinpoint it I’ve changed as a person I’ve changed I’m not probably the same person I’m not the same person I was.</td>
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<td></td>
<td>Margaret: But I tried to get my husband to tell me and I still can’t, he doesn’t seem to, I think, his perception wasn’t that I was very different, as a person. But my personal experience was that I was very different (Margaret).</td>
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<td>Margaret: I think that deep down the person I am hasn’t really changed. I said I’m a bit more forgiving both of myself and others, but that could be just life couldn’t it.</td>
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<td></td>
<td>Rose: Yes, I just think I’m thoroughly confused about what kind of person I am really.</td>
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<td><strong>Conflict</strong></td>
<td><strong>Being constrained by Illness</strong></td>
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<td>Margaret: It’s exactly like the circumstances are such that you’re caught, there’s no way out, you’re trapped, you can’t put on a burst of energy to get to where you want to go because err, the consequences of that could set you back months.</td>
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<td>Margaret: The essence of me still exists but it doesn’t work as well as it used to.</td>
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<td>Margaret: I mean, I feel like, you know, I have all these great ideas and...</td>
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<td>I, I can't put them into execution and you know, I feel like I need two right hand men women, whatever, to do all the leg work, but I don't have them, all I have is me and I'm faulty, broken in some sense, I don't work as well as I used to.</td>
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<td>Lucy: I'm just not where I want to be you knowing um, I can't see a vision of having those, in order to choose those things.</td>
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<td>Rose: Yeah this thing that will insist on controlling my life yes.</td>
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<tr>
<td>Rose: Yes I think I think of it as this annoying separate entity that follows me around and governs my life and makes me a different person from the person I want to be.</td>
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<tr>
<td>Jim: Dunno, just frustrated, sad sometimes um it is mainly frustration at being in this feeling trapped in this little world and you can't get out of it and there's no answer to it.</td>
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<td>Jim: It's not as if you're going off and doing what you want to do going on holidays, going and playing golf well you're not, you're trapped in your own little world, it's not much fun.</td>
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<tr>
<td>Peter: Um, I think the fatigue has meant that thinking and doing is just put to one side.</td>
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**Construction of the pre-illness self**

<p>| Margaret: I had a real ability to concentrate for many hours, um, because I was very focussed and I could, say I'm here I want to go there and I would just do it. |
| Margaret: I used to come and sit in my office and I’d work for 3 or 4 hours, whatever and you know just sit there and just go through all the work there was no question of that. |
| Margaret: Right, well [pause] the kind of person I am, I’m the kind of person who likes to do a lot of things. |
| Margaret: Whereas back in the day, I’d just sit down and do it, whatever needed to be done and I used to, you know, work at my desk for 7 hours a day, I had to just getting through it, sure as you do if you have a certain amount to do and you’ve fallen behind, you just sit down and you do it. |
| Margaret: Well I never thought I was particularly, you know, exceptionally bright, I think I was particularly hard working. |
| Emily: I, I used to do loads of athletics and just be one of those annoying kids who if there’s one way of getting from A to B, they’d never take the easy way they’d always bounce or jump or hop [laughs]. |
| Emily: Um, I’m the kind of person who just loves being out and about and usually by foot or on bike. |
| Lucy: But you know I was quite a sociable person and you know I enjoyed my job and I don’t know I used to do a lot of things really, I had a lot of interests. |</p>
<table>
<thead>
<tr>
<th>Lucy:</th>
<th>Um, I used to like photography [shows pictures on wall], that was something I started just before I got ill so I haven’t actually got into it properly but yeah um travelling um we used to go to [names location] quite a lot and drive through to [names location] um and go snowboarding and that sort of thing so um yeah I liked to you know, that sort of thing...I’d been I used to go to [names location] travelling around for a few weeks.</th>
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<tr>
<td>Lucy:</td>
<td>Um, I had a full time job and I’d just been promoted um I had my own car, I shared a flat with my partner um I also had money, well I had you know my wages and I had my independence in that respect, I could go, you know if I needed something I could go out in my car and I could arrange a holiday if I wanted to, you know a short break go out for sessions with my friends that sort of thing.</td>
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<td>Jim:</td>
<td>Whereas before as I say I was quite sporty, kind of get up and go.</td>
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<td>Jim:</td>
<td>Um yeah I’ve always been sort of 50:50 you know when I was married and all that I wouldn’t sort of say that’s your job and that’s my job I’d mix in we’d do everything together.</td>
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<td>Rose:</td>
<td>Because I know I’m an intelligent person.</td>
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<td>Rose:</td>
<td>I would also consider that my brain is the location of my identity.</td>
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<td>Rose:</td>
<td>I think of myself as an outgoing, sociable person.</td>
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<td>Rose:</td>
<td>I felt such an odd ball and that really added to this sense of not having an identity anymore because I’d given up work but now I feel I’m sort of perhaps working my way.</td>
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<td>Peter:</td>
<td>I had um secondary modern education quite a good one I think, I started work at fifteen qualified as a [names profession] and had a good career in the [names profession] industry until I was 50.</td>
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<td>Sam:</td>
<td>I’d got what I wanted and I was very active and I had lots of friends, I enjoyed doing stuff, I’ve always been a ‘doing’ person and I’ve never, ever been very good at not, at sitting.</td>
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<td>Sam:</td>
<td>You know I used to be quite fit and active before and I used to play netball and all sorts before.</td>
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<td>Margaret:</td>
<td>I couldn’t do the ‘doing’, if you see what it is, um, I couldn’t concentrate, a lot of the time you just don’t care, I mean you care, but you don’t care enough, that’s how it feels like, it feels, it’s almost like it feels like you lost yourself.</td>
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<td>Margaret:</td>
<td>Well it wasn’t sudden, it was a gradual problem, but to read you have to be able to concentrate and focus and I couldn’t, so that ability to concentrate and focus which was critical to me being the kind of person I was because I was an academic was gone.</td>
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<td>Margaret:</td>
<td>Now it’s really funny because um when I was little I used to organise my mother, you know I’d get fed up of something being untidy, like where the telephone like where the telephone kiosk, because my father had to have his own phone and we had our phone and there was...</td>
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like a big set of drawers and so on and there was like a piece of paper and I'd just sit there and I'd organise it, I'd just go through and I'd say let's throw this out we don't need this anymore and that's the kind of person I am you know, very organised. I'm not like that anymore.

Margaret: I had a career built around it because I loved to do it, um, but, so giving that up was quite, you know a hard thing to do but I really couldn't do it anymore, um and as I said, you know I have a friend who I used to work with and she and I talked about working together, doing some research together, and I was supposed to read this research book [referring to a social psychological research text book] this summer and I just haven't, I just had so much more energy. You add energy and ability together and you can go from A to B very quickly.

Emily: Um, I'm the kind of person who just loves being out and about and usually by foot or on bike and there's just no way that I can do that.

Emily: I've already tried to go to University, after week five I had to come home because I got fresher's flu and two other viruses at the same time.

Jim: Um yeah I've always been sort of 50:50 you know when I was married and all that I wouldn't sort of say that's your job and that's my job I'd mix in we'd do everything together, um and having that sort of taken away from you is another part of the frustration.

Jim: Oh it's the ability to be yourself, I can only do certain things, I can't just go and do what I want to do I have to think about it all the time whereas before as I say I was quite sporty, kind of get up and go.

Jim: I was made redundant though the [names employer] to be fair to them didn't just kick me out the door which they could have done because I wasn't fit for work.

Jim: Yeah, you're not part of what you should be or what you were before it's almost sort of not cast aside but you're away from it at the moment you can't get back to it you know you keep being invited to different things but you can't actually.

Lucy: I think the fact that I don't have my job anymore um, I'm not as active as I used to be, not socially, I don't really have a social life, I don't do any of the things I used to do, I don't sort of travel [indecipherable] I used to go snowboarding and I don't do that anymore.

Lucy: And um I don't know it's when you have your independence and then you start to lose it even when it's just silly things that you wouldn't normally notice it means a lot.

Lucy: I'd been I used to go to [names location] travelling around for a few weeks that's not something I could do now.

Lucy: Well yeah I guess so I suppose they were just part of my life, they were just things that were there and I just thought well that's what you know, that's what I wanted to do um, that's what I was a part of, and of course that stopped.

Rose: Because I know I'm an intelligent person and yet I know that these days I can come across as somebody incredibly stupid and I find that distressing , when like if I'm in a shop and I'm tired and somebody
says something is three pounds twenty nine and I open my purse and I don’t know what three pound twenty nine looks like and I’m fussing and taking ages you know trying to figure our what those words mean in relation to what is in my purse and I can feel their impatience or when I’, making phone calls if I ring up to try and find out about something I can hear people sigh at the end of the phone.

**Rose:** The whole thing was a total failure and I thought you know I can’t even do this simple project, but it’s trying to get an overview of how you, how all those components fit together my brain just couldn’t do it...so that goes back to what I was saying before about thinking that I’m an intelligent person and yet being incredibly stupid.

**Rose:** Yes, I just think I’m thoroughly confused about what kind of person I am really, um I, I think of myself as an outgoing, sociable person yet when I am in company now, I can often be extremely quiet.

**Sam:** So I just couldn’t get better and ended up having to go home and had to have a year off University.

**Sam:** Um and the commuting into [names location] wasn’t really the most ideal situation and I did all, like the exams were fine it was just I really didn’t like my job and I was sat down all day which didn’t do my back any favours either so at the end of my time off I had, I decided to not go back.

### ‘Negative’ Consequences of Shifting Self

#### Loss of confidence

**Lucy:** I’ve definitely lost my self esteem and some of my confidence definitely, because of feeling like a failure I suppose so those are things I would like to see improve.

**Lucy:** Um, well self-esteem comes with everything that’s happened really, the illness um my prospects are quite limited.

**Lucy:** Well, I don’t know, I feel like a failure really. I think the fact that I don’t have my job anymore um, I’m not as active as I used to be, not socially I don’t really have a social life, I don’t do any of the things I used to do, I don’t sort of travel [indecipherable]. I used to go snowboarding and I don’t do that anymore.

**Lucy:** My self-esteem and my confidence it does influence how I feel about myself as a person and the fact that I do feel a bit of a failure in that respect.

**Rose:** An embarrassing thing, definitely an embarrassing thing [referring to illness]. Well because of the way people um, um because of other people’s attitudes the way they often behave and because of the when I first got ME it was much more of a physical thing than a mental thing and then when I had the relapse I had a lot more cognitive problems and so it’s, it’s variable at different times but um there are lots of times when it’s very hard to talk and explain things and you know I forget words and I forget what I’m saying in the middle of a sentence and all of that is highly embarrassing.

Contemplating the Future in CFS: A Grounded Theory Exploration of the Experience of Self and Contemplation of the Future Across Individuals with Chronic Fatigue Syndrome
Frustration

Rose: So that is a real knock to the confidence when you do stupid things or you can’t talk properly and um the walking thing has been a blow to the confidence because um if I’m on two feet and I’m out and I’m having difficulties then I kind of shuffle, I sort of forget how to pick my feet up, it’s a curious thing.

Rose: Yes I was this sort of misfit in society because I wasn’t um old, I didn’t have small children to look after, I wasn’t overtly disabled you know there weren’t very obvious signs of why I shouldn’t be at work and so it all contributed to my thoughts about being a waste of space.

Rose: So yeah there’s a huge contrast between the before and the after, I was a much more confident person before um, and I don’t know

Margaret: As I said it’s immensely frustrated because I’ve had to say I will never have the successful career that I was aiming for.

Emily: My sleep pattern is disrupted, I only get half a day awake this means I can’t get everything done in the day that I want to...I go to bed at and get up at 1 as I need hours sleep and that leads to a lot of frustration.

Emily: That’s what I find, that may just be my case but I find that I’m wanting to do things before I can actually do them um physically and that’s when it gets really frustrating and I think probably one of the biggest emotions in my life is frustration, you feel it all the time about so many things.

Emily: Although I was having to very carefully manage myself, there wasn’t an enormous amount of frustration because I was doing so much more than in the previous 7 years.

Rose: And in order to be able to go to that class I have to spend all day Tuesday forcing myself to do nothing which is really boring and frustrating and er I have to have to arrange.

Rose: And if I’m talking I am so slow at you know retrieving the words so that’s frustrating you know...if only I could achieve better there, you know I’d be happier with that.

Rose: And ring her or I can lie down and read the post or something like that so I don’t feel like the time is totally wasted, frustrating and achieved things.

Jim: I suppose it’s days when I’m feeling better within myself I’ve never really thought about it you’ve just put it but some days I am more frustrated than others so it’s just, I don’t know.

Jim: Um yeah I’ve always been sort of 50:50 you know when I was married and all that I wouldn’t sort of say that’s your job and that’s my job I’d mix in we’d do everything together...um and having that sort of taken away from you is another part of the frustration.

Jim: Well frustrated really a bit sad about it the other thing I do is rest a lot and sleep a lot, I don’t see the mornings very much at all um and then I get annoyed with myself about that, think I’m sleeping my life away.
<table>
<thead>
<tr>
<th>Jim:</th>
<th>Dunno, just frustrated, sad sometimes um it is mainly frustration at being in this feeling trapped in this little world and you can’t get out of it and there’s no answer to it.</th>
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<tbody>
<tr>
<td>Peter:</td>
<td>At the moment and I think I got it out three weeks ago um it just doesn’t happen and this is so frustrating.</td>
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<td>Sam:</td>
<td>Um the frustration, that’s always been my biggest trouble, I’ve always because I’m such a determined person and such a kind of get on and do it time person I always, always did too much too soon.</td>
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<td>Sam:</td>
<td>The frustration of not being able to do stuff because although like my concentration got far worse I used to my concentration got not very good and my patience as well I used to be able to sit down and do absolutely particular things for hours and hours and hours and although I’m better now than I was I still couldn’t sit down and do stuff for as long as I used to be able to um and I used to get so frustrated that I was still trying to do those things and then of course muck them up and um somebody else had to pick up the pieces after everything and the same with kind of being able to do stuff I remember the it was still during that first year...because I’d been I used to be very active and play netball and go to the gym and all stuff before I got glandular fever.</td>
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APPENDIX 12

(Quotations Corresponding to the Major Category of: Making Sense of Illness Experience)
Making Sense of the Illness Experience: Associated categories, sub-categories and selected quotes.

<table>
<thead>
<tr>
<th>SUB-CATEGORIES</th>
<th>SUPPORTING QUOTES</th>
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<tbody>
<tr>
<td>Questioning Illness</td>
<td>Margaret: Um I was it's difficult I look back and I think, I was really ill but I was also depressed because I was really ill, was I just depressed?</td>
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<tr>
<td>Validity</td>
<td>Margaret: I used to be a lot harder on myself, before I actually knew I had Chronic Fatigue I really, really believed I was avoiding the work.</td>
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<td></td>
<td>Emily: It gets to the point that you don’t know whether you are actually ill or not. You think maybe I’m just going mad, that it seems like I can’t do all of these things um maybe I can really, that I’ve just got into a way of thinking that I can’t.</td>
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<td>Rose: Also because you get good times with ME, you know there are some days when I feel really good and I don’t have to rest very much and I can go out and walk more and do things and those are the times when the real enjoyment and joy at being able to do that is slightly marred by this little voice at the back of my mind which says well there’s nothing wrong with you then is there.</td>
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<td>Rose: Yes, yes that’s right, you know instead of being able to whole heartedly enjoy the good times it’s at the back of my mind that there’s nothing wrong then.</td>
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<td>Rose: But then there is also a sort of feeling mixed in with it that I’m a charlatan and that I’ve been conning people so it’s a mixture of the two really [talking of the influence of symptom improvements].</td>
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<td>Rose: You know you can do this if you put your mind to it and it’s the same as everyday when I step outside the door to go out, nowadays I can start walking at normal speed and it doesn’t hurt to walk and so I can just walk like everybody else can and when that happens I think, well there’s nothing wrong with my walking then it’s not a problem</td>
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<td>Peter: I didn’t want to solve it in ten years time I wanted to prove now that it wasn’t my head you know I desperately didn’t want it to be my head.</td>
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<td>Sam: [crying] That there’s actually nothing wrong because physically you’re, there isn’t anything wrong you know at the moment I’ve got a sore throat and my glands hurt but there’s nothing wrong with me though.</td>
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<td>Sam: And it is horrible knowing that you’ve got physical symptoms but there’s no explanation for them, there’s nothing wrong and you’d almost rather I’ve got a sore throat and my glands are up because I’ve got a virus you know there’d be an explanation</td>
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|                         | Sam: I don’t know really um I think it’s possibly partly because I
thought I’d got pretty much better and it was gone I think maybe I’d started to convince myself that maybe it was all in my head.

Sam: Which I suppose no-one ever really knows the answer to and I suppose it depends from one person to the next um...and is it all in my head?

Interviewer: What makes you feel it’s all in your head?
Sam: Because I don’t always feel like it.

Margaret: Was I just depressed? No I know I was really ill because I had the measurement that I was really ill.

Margaret: Right OK and in some people it isn’t, it’s pretty clear to me that mine was not psychological mine is physical. It may have psychological aspects to it but it is proven to me that I have a physical problem.

Lucy: Because if they knew what it felt like, it’s not like when you’ve had a late night or you didn’t have a very good night’s sleep and you get up in the morning you, you know might be really tired but you manage to function anyway it’s not the same thing.

Peter: But because of these tests I had up at [names location] [X] years ago where they stuck wires on my head and put me on a computer and I could prove that I could go to sleep within two to three minutes and stay asleep for half an hour this is what I said at [names facilitator]’s group I’m the luckiest one there because I’ve got a bit of paper that says I’m ill or I have a problem, none of the others have got a bit of paper because, they can’t prove it.

Peter: And I, I said to him that it’s been suggested at work that I might take a bike to work or go swimming during the day to keep me awake and he said well no that would add, the tiredness you’d get from the exercise would add to the natural tiredness you get.....he said why, I said well I’m falling asleep about 8 times a day and I fight it you know you shake your head and you stand on your head and you run on the spot and you sit down and you feel tired again and you can’t work and after 40 minutes of struggling um it seems a waste of time and he said well, what you’ve got to do is go to sleep when you feel tired and enjoy it, the best prescription ever because you feel tired and you go to sleep, sleep for 10 minutes and you’re fresh again and there’s no guilt.

Interviewer: You’ve had some, you know they’ve done a test and they’ve found kind of biological?
Peter: Oh yes and this piece of paper says they have.
Peter: The letter said we don’t want to see you before [gives date], why [date] I don’t know because I officially retire in [gives date] this year but the letter it’s like wow I’m free I’m not conning anyone [referring to medical support letter in claiming benefits].

Sam: [interjects] And I suppose when I felt like it more and it was more constant then, then I felt the physical kind of symptoms more.
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<th>Questioning agency</th>
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| **Margaret:** Now I don't know if it's because, it's entirely me, is it because I've been so busy with the building work, which has been really...or am I just avoiding it. This is the kind of thing I ask myself regularly. Am I avoiding it because it is difficult? Am I avoiding it because it means re-engaging or am I avoiding it because I just can't do anymore than I am currently doing?  
| **Emily:** And it is infuriating to me that this is what I've done and there are people around me that I know with CFS who have gone out partying every night felt completely ill the week after and done nothing and got better in two years and I'm here doing everything correct and [X] years later I'm still the same pretty much [laughs]. I don't know whether that's just me whether I would have just not got better whatever or whether.  
| **Lucy:** You, you're not trying hard enough, you know that sort of thing you should go out and exercise and you should go to the gym, you know that sort of thing which is quite heart breaking.  
| **Rose:** Well there's nothing wrong with you then is there, you know you can do this if you put your mind to it.  
| **Rose:** Yeah, I mean, well when I was a teenager I can't remember consciously thinking Oh I better be ill all the time but looking at it now so many years later I kind of feel like maybe that was the mechanism that went on and now, I don't think I think myself back into being ill, I think what happens is that just I'm having such a good time when I'm feeling better that I ignore all the pacing rules and push the envelope further and further and then I fall apart so I'm not aware of perpetuating it by my own thoughts I don't think but then maybe in 30 years time when I look back on this.  
| **Rose:** It's at the back of my mind that there's nothing wrong then and I think well I could get a job then I could go back to work. [Talking about the 'good times'].  
| **Rose:** Um because I struggle so hard with my own feelings, I struggle so hard to [becomes tearful] convince myself that this isn't something I can just snap out of and I spend a lot of time, still, beating myself up over it and thinking that I should be able to do things.  
| **Rose:** And it's the same as everyday when I step outside the door to go out, nowadays I can start walking at normal speed and it doesn't hurt to walk and so I can just walk like everybody else can and when that happens I think, well there's nothing wrong with my walking then it's not a problem.  
| **Rose:** And um I was blaming myself a lot that it was my fault um that you know if I just pulled myself together I'd have loads of energy, I can do what ever I like and you know this is all very silly.  
| **Rose:** So I'm not aware of perpetuating it by my own thoughts I don't think but then maybe in 30 years time when I look back on this [Referring to own role in illness].  
<p>| <strong>Jim:</strong> They may have initially thought because they don't... |</p>
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<td><strong>Margaret:</strong> I really, really believed I was avoiding the work and um, I actually went to see someone about it, you know um because I thought, you know, I had a real problem, that somehow I wasn’t engaging with what I had set out to do but since I’ve been proven to have Chronic Fatigue and I understand the chemical impact of it on my body I’m a little more forgiving.</td>
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<td><strong>Emily:</strong> Because you know that you’re just feeling so unwell that there’s no two ways about you going out, so you don’t have a choice and therefore you don’t feel particularly guilty about it.</td>
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<td><strong>Margaret:</strong> And he didn’t know that I had had a question mark over my health well he knew but he didn’t understand it I think a lot of people don’t understand it.</td>
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<td><strong>Margaret:</strong> He says things like well “you will push yourself if you really want to do it” but what he doesn’t understand is that there’s a consequent ‘cost.</td>
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<td><strong>Emily:</strong> But I know that other people with CFS find this a really big problem that, people think you’re just unreliable and well you are but through, through no fault of your own.</td>
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<td><strong>Lucy:</strong> I don’t think he understood how complicated that was and I think that I also felt this pressure, you know this awful pressure which didn’t really help either.</td>
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<td><strong>Lucy:</strong> I don’t really know, I just kind of think maybe it’s because it was called the ‘yuppies disease’ or something, I don’t know ‘yuppy flu’ or for a long, long time um but it’s you know it’s not, it isn’t and you know people, I don’t know people can just be ignorant actually, they can be quite ignorant. If they’re feeling really healthy and well and their life is going really well and they look at you and think well I don’t really understand.</td>
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<td><strong>Lucy:</strong> And also because people don’t understand, you know what it’s like and people get frustrated with you, you know friends and my partner did get frustrated with me over it um and he told me to get an exercise bike and he bought me it was quite hurtful actually, he bought me all these um books on ME. Yeah you’re just reading about things you are going through and he must have brought me about 5 or 6 of these books and he kept saying on should read them, read them and I just thought why don’t you read them, you know then you might understand.</td>
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<td><strong>Lucy:</strong> They couldn’t relate to me and although I understood their lifestyle I couldn’t participate in it I wasn’t able to do it. It was just sort of a complete, brick, brick wall really.</td>
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<td><strong>Lucy:</strong> And doctors, doctors definitely, because um I mean it’s not really relevant but sometimes, when you go to the doctors and you probably might have noticed that you have a very limited amount of</td>
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time and if you are feeling really and sometimes you don't feel physically up to conversation and then when you try to explain how you feel, you feel a bit rushed and um I mean honestly, I don't think there is a great deal of understanding I think GPs should definitely should perhaps be forced, not made to, but perhaps should be given some information some information definitely, or maybe even some case studies of other people so that they can compare them, read them and somehow find a middle ground you know [indecipherable] yeah I think that's definitely important.

Lucy: The pressure it was just awful it's just pressure to get better quickly you know hurry up and get better, get better quickly, you can do this, you can do that, which was quite scary because although I wanted those things I physically knew that, you know I couldn't tell if that was going to happen quickly.

Lucy: After I had separated from my partner because it was a big pressure when I was living with him it was a big pressure to go back to work um and I was worrying about how I would cope, because I did actually return to work after 6 months after the first 6 months or maybe 7 months I made the ridiculously stupid decision of going back to work.

Rose: As well an illness that is not very well understood.

Rose: I do take time to explain that I can borrow energy but it hits me afterwards and I do, I do try to convey to them.

Rose: And they're always asking us to come over and um it's hard to make them realise how difficult to do a long haul flight and then do lots of travelling around while I was there and lots of being with people and um one of those friends has been over and she stayed with me but only for two days at a time each time on route to somewhere else so for those two days I can borrow energy and she doesn't see me for the week that I'm in bed afterwards and so there's and I have a friend in [names location] as well whose been over to stay several times but again only for a couple of days each time and she's always saying you know why don't you come to [names location] and um it's hard to make them understand that although I seem one way,. I'm actually another way.

Peter: I mean in fact, this thing with my sister, I don't want her to ring me and it's a terrible thing to tell someone that you don't want them erm because I don't think she'll understand.

Interviewer: Do you feel that's something quite generally... that people don't understand?

Peter: Oh, yes, yes.

Sam: Not really, I think, when I was at University and had to come home I was living with one group of girls and all the time I was struggling they some where really good and in fact the two that weren't very good like when I needed to go to sleep they were really noisy and everything they were two medics actually and you kind of think out of all the people that should they were like the least sympathetic.

Sam: and I said yeah, I've got to go I don't even care if we haven't had food we're going because we promised that we'd go and I think
Feeling disbelieved

[partner’s] parents thought that I was an absolute you know weirdo [laughs] because and his dad was like...and I just said to him you know I can’t do my job if I don’t go to sleep and so I think in a way they think that um I’m a bit strange?

Lucy: There is definitely stigma attached to it, that you’re um a weak person or you’re lazy or you, you’re not trying hard enough, you know that sort of thing you should go out and exercise and you should go to the gym, you know that sort of thing which is quite heart breaking.

Lucy: I feel, because I get the sense that a lot of people don’t think it’s a real illness I feel and it’s so stupid but sometimes I feel guilty.

Lucy: Mmm because, because people just think it’s not a proper illness you know, because you can’t take medication for it.

Good days masking illness

Lucy: And then maybe one day you can be a little bit better, you know that doesn’t make sense to them, it doesn’t make sense that you’re tired, they just think well you’re tired, it’s just tiredness, what’s the big deal about that you know.

Rose: That’s hard to deal with or if I use shop mobility than I feel very exposed because I’m on this buggy and um people, people make lots of um people assume that walking aids like that are for people who can’t walk at all, not for people with limited mobility and that was a big thing for me to overcome myself and then I still find there are all these people who have that attitude so it’s almost like um if I can walk a bit I shouldn’t be using something like that, you know.

Jim: Well, like I went to see my mum and that on, I come from a big family...on mother’s day and they were all telling me how well I was looking and all that.

Jim: [interjects] I had to tell them to shut up in the end because I said I’ve been feeling poorly over Christmas I’d picked up a bit I was feeling a bit better and it had all sort of gone, collapsed again and went backwards, I’d been feeling really bad the two weeks previous to mothers day and er for them you know to go they were being...only telling me what they thought, they were all saying how well I looked so in the end I said shut up I feel absolutely diabolical, I might look alright which is part of the problem with this illness.

Outward appearance masking underlying illness

Jim: You can’t get it across to people but because you don’t look ill you know people come to visit they expect you to look ill um and I say to them you know if you spend some with me then you’d realise, it’s not quite as it looks.

Jim: Some of which puts be off because I don’t look ill [talking about others providing encouragement].
Jim: Because I didn’t look any different and people are used to you being how you were and they can’t quite grasp it they want to just tell you pull yourself together you know.

Jim: Because you don’t look ill people relate people being ill to looking bad if I came out in a rash all over they’d probably say oh you’ve got Chronic Fatigue but then because you haven’t but then people have migraines you can’t see that can you and people believe all that

Peter: Because we all look fit you know why are we off work, you know why are we here.

Sam: I think it’s just I think also because it’s something that’s not, you know I always say it’s not like you’ve got a cast on your leg is it and it’s just...[becomes tearful] you don’t know if people are going to understand.

Rose: To [names location] and um it’s hard to make them understand that although I seem one way, I’m actually another way, you know they see a snap shot and they don’t see the wreckage that gets left behind.

Rose: Whenever you meet people it’s always “oh don’t you look well” and that hurts so much when you feel absolutely terrible, you know, I interpret don’t you look well as well there’s obviously nothing wrong with you is there.

Margaret: I’m not doing nothing, which is why I get annoyed with them when they tell me I just do everything I want to but it looks like that to them.

Margaret: The sub-story is you’re just using that as an excuse so it is hard.

Margaret: They actually look at me and, I don’t know whether it’s a convenient excuse or whether they really believe it but they think I have a cushy life. They think [voice wavers] I don’t do a job so I get to do what I want to do, so why can’t they.

Lucy: That you’re um a weak person or you’re lazy or you, you’re not trying hard enough, you know that sort of thing.

Rose: Um there was one person that was a friend of a friend and we used to go out all together and this women always used to say “Oh I’d like to be a housewife, I’d like to have a man look after me...I’d like to not have to do anything all day long and she said that every single time we met and I’m sure that was a dig at me for being at home and not working.

Rose: Oh I’d like to be a housewife, I’d like to have a man look after me, I mean the word housewife was really an anathema to me because it’s not something I identify with, I don’t see myself as a housewife, I wouldn’t have ever chosen to be a housewife.

Rose: Well I assumed she’s one of the people who think that this is
Peter: She started onto a theme about psychosomatic and er she didn't know what it meant.

Jim: Went, we had a walk round the pub and when we came back I heard him say to [names partner] while he thought I was out of ear shot, I heard him say to [names partner] my partner it's an act isn't it and I thought to myself you just don't understand.

Jim: You know in the early days I'd end up in tears sometimes and I couldn't explain it to people how bad I was actually feeling and er even my brother in law who lent me the hedge strimmers he said 'I feel like saying just getting hold of you and shaking you and saying pull yourself together you know'

Jim: It mind sound great to have two years off of work but it's not, you know people might think you haven't got to work for two years but it might be all right initially for the first few weeks but then it starts getting boring and driving you mad, it's not as if you're going off and doing what you want to do going on holidays, going and playing golf well you're not.

Justifying Illness

Margaret: because what they would like to do is sit home and go on the computer and they don't understand. I mean I say I'm not well and you know I've got Chronic Fatigue and they go" you just, you know, yes but".

Emily: people think you're just unreliable and well you are, but through, through no fault of your own.

Emily: I suppose you end up comparing yourself to other people a lot, would such and such a person feel the way that I'm feeling in this situation or am I feeling an excessive amount of this of X emotion because of the things that I've been through and because of having CFS.

Jim: I said well [names brother in law} if it was that easy I'd do it I don't want to feel like this, who would want to be mooching around like an old man.

Jim: You know you don't want to be like this for the rest of your life 'cos it's no fun.

Lucy: Because I didn't you know, I didn't ask for this. It's not something I want at all I can think of so many other things I'd rather have than have this, you know I'd rather have every bone in my body broken and just take my chances than just end up being like this, so it is really annoying it is frustrating when you feel like that, get that impression about people.
**Pathologising symptoms**

**Rose:** I do take time to explain that I can borrow energy but it hits me afterwards and I do, I do try to convey to them.

**Margaret:** How can I explain this feeling, it's cellular, you don't just feel tired you just feel like every cell in your body is saying "rest", that's the only way I can explain it, you know it's just [blows nose] it's just um, I can't remember what it's like to feel normally tired.

**Margaret:** Sure as you do if you have a certain amount to do and you've fallen behind, you just sit down and you do it, OK you may not like doing it all in one go but you do it. But you'd never think "Oh, if I do this, then tomorrow is going to be a wipe out" do you..?

**Margaret:** Do you have that? You're tired and you stay tired and then you go to sleep and you wake up. And it's a known fact that Chronic fatigue can affect your sleep and you will feel tired, because it's like a low grade infection all the time.

**Emily:** It's not the, the normal stress reaction it will trigger something to just keep, the stress reaction just going.

**Lucy:** But they were very rare and occasional but they weren't, when I say good sort of days I don't mean that they were, I didn't feel normal like I did before I got sick, you know before I started. I've never felt, I've never had a day where I felt as well as I did before it started.

**Lucy:** Because if they knew what it felt like, it's not like when you've had a late night or you didn't have a very good night's sleep and you get up in the morning you, you know might be really tired but you manage to function anyway it's not the same thing.

**Margaret:** Because that's what it's like to try and cope with, what a normal, if you were normally well you would just push yourself and get it done, you know you put in a hard day and you'd say "OK I've made big strides today."

**Margaret:** [Interjects] You see maybe it's me, that's the problem, I don't know what other people are like with Chronic Fatigue, maybe they don't experience the same problems that I do. For a start they may not have the mental fogginess um which no question impacts how I experience my life um, there's no way.

**Emily:** I suppose you end up comparing yourself to other people a lot, would such and such a person feel the way that I'm feeling in this situation or am I feeling an excessive amount of this of X emotion because of the things that I've been through and because of having CFS.

**Emily:** And then you go and try to do something and you realise no I really can't, or you see somebody else doing something that there's no way that you could do it and it sort of brings, gives you a reality check.
<table>
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<th>Emily:</th>
<th>Is that you don't get bored, because it's the best way I can describe it is it's like that point that you get to in the evening, like a normal person gets to in the evening, when you're just starting to get really sleepy and you're thinking I can't do anything else I really need to get to bed and you feel like that all the time.</th>
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<td>Emily:</td>
<td>Where I'm at the moment is that I definitely do have a much lower energy than everybody else, I don't get the muscle aches or the sore glands or things like that, my concentration and memory can be a bit poor sometimes but a lot better than it has been really.</td>
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<td>Emily:</td>
<td>and what's more is that, there are very few people who have had it in quite the same way that I have apparently...[discussing anxiety associated with illness].</td>
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APPENDIX 13

(Quotations Corresponding to the Major Category of: Strategies for Negotiating Self-Illness Conflicts)
Strategies for Negotiating Self-Illness Conflict: Associated categories, subcategories and selected quotes.

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<th>MAJOR CATEGORY</th>
<th>SUB-CATEGORIES</th>
<th>SUPPORTING QUOTES</th>
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| DISTANCING     | Resisting self-illness changes | Margaret: Physically, well I was physically active but I would come home and I would collapse (laughs) but um I can’t explain it um I didn’t connect the two.  
Margaret: Yes and so I didn’t actually believe him and I carried on trying to do stuff, you know, I actually I herniated my disc and I couldn’t sit for three months, that was just as I was going to go back that [gives date], I herniated my disc and um, I couldn’t work.  
Margaret: I can watch TV, I’m reading, OK it’s not serious stuff although I do have a serious book out which I am supposed to try and read about [gives title of books related to profession].  
Lucy: It’s er it’s a complete, it’s a complete change really, it is a complete change, my life is completely different, it’s quite staggering really, it’s not you know how it was and it’s not something that I want to get used to either.  
Lucy: It’s not, it’s not acceptance that it’s never going to happen and I won’t do it so I might as well not worry about it, it’s not like that.  
Interviewer: And it doesn’t sound like that’s something your totally comfortable with?  
Lucy: No, no it isn’t because it just reinforces to me you know my situation…it just reinforces everything.  
Lucy: I didn’t actually realise at the time that I could have um claimed benefits, ‘cos I have never done that before and I didn’t realise that I should have been doing that so what I was doing and I think also, deep down and I think it was just like admitting defeat in a way for me, it was just like admitting defeat so I did stupid things like um I used my credit card and maxed it out and that type of thing, just to try and appease the situation.  
Rose: Trying to behave like you’re the same as everybody else and then every so often something crops up and you have to say oh actually I can’t do that.  
Rose: I mean the word housewife was really an anathema to me because it’s not something I identify with, I don’t see myself as a housewife, I wouldn’t have ever chosen to be a housewife and um so I always have this problem when I mean, it shouldn’t be a problem I should be able
to just use the word, but when it comes to filling in forms and people saying to you what’s your occupation, I always stumble over that one um because I don’t want to use that word.

**Rose:** Trying to behave like you’re the same as everybody else and then every so often something crops up and you have to say oh actually I can’t do that.

**Rose:** And I couldn’t get it into my head that this was a more long term even though I’d been through it once you know at the very beginning you know I’d had a longs period when I was in bed and then I had a long period when I had a, it was like a period of mourning where I’d been bereaved ‘cos I missed my job so much and I had to take ill health retirement and that was such a huge blow and it was so hard to come to terms with having, ‘cos I’d so enjoyed my job

**Sam:** So during that time obviously in hindsight I can kind of tell you know why I got it was very frustrating obviously um I wasn’t sure I’d be able to go back and I kind of did eventually go back not particularly under the advice under the doctor but I knew it was kind of like, it was now or never time, so I knew I had to do it um and then [becomes tearful] yeah I kind of, I managed to get through University and then I started working and I was alright but I was still kind of I worked, I slept and that was it and um and then.

**Margaret:** It does, yeah I mean, you try to plan um and I know I’m very strong minded and there are times when I will literally override what my body is saying.

**Margaret:** I actually realise that I’m not that risk averse because there will be times when I’ll push it, but if you want to do and there are some things you want out of life and you’re only prepared to accept so much diminution of it and um.

**Margaret:** And one of the interesting things I’ve learnt and actually this is typical of me, if I gave in to my tiredness all the time I’d be asleep half of my life, I fight it and I realise that I’ve got into the habit of fighting it which is not good, you really need to not fight it, but because, if you don’t fight it then you don’t have a life at all.

**Margaret:** And she said” but I want to complete on the same day” which was one week late, so I had less than 2 weeks to clear the house and it was oh it was like late October which is again a bad time and um, I went to er I did it, my husband was working Full-time up at the University, he couldn’t do it, I really pushed myself to, to do it.
Margaret: so I don’t sleep as much as that because, I want to do things and I want to, I don’t want to be asleep all the time.

Rose: I think what happens is that just I’m having such a good time when I’m feeling better that I ignore all the pacing rules and push the envelope further and further and then I fall apart.

Rose: I think to myself this weekend we can go out, we can do this we can do that and in my mind I’m planning all this stuff and of course it doesn’t happen because I haven’t got any more energy at the weekend than I have in the week and if I go shopping by myself I know I can only manage about half an hour and yet if I go with [names husband] I kind of have this naive assumption I’m going to be able to stay out all day but of course I can’t um.

Sam: Um the frustration, that’s always been my biggest trouble, I’ve always because I’m such a determined person and such a kind of get on and do it time person I always, always did too much too soon, always and it was always kind of knowing my limitations and it took me a long, long time to work out what my limitations were and I knocked myself back so many times.

Sam: I don’t when we’re in company but I’m just yeah I do switch off I think but it’s by doing, by doing stuff rather than sitting down and relaxing which obviously doesn’t help the whole fatigue thing so no I’m still not very good at doing that.

Sam: I’ve often gone in when I shouldn’t have gone in and it’s not just me that does it at all, you know it’s everyone and the [names profession] they’ve hardly got a voice and you think ‘go home’ and we can all say it too each other but we all do it.

Margaret: But I mean, I’ve, I’ve had lots of ideas you know my brain hasn’t stopped having ideas, it’s perhaps they are not as good as the ideas I used to have, I don’t know, it’s very difficult to assess that and then, ideas come, I know that they don’t I can’t sort of you know whip them up.

Margaret: OK I’m not dealing with academic institutions I’m dealing at a much lower level but um, I er I just don’t have time and energy to waste time and energy.

Jim: And she pushes the trolley ‘cos it tires me out, it sounds pathetic doesn’t it but that’s what it’s like.

Lucy: I didn’t feel normal like I did before I got sick, you know before I started. I’ve never felt,
I've never had a day where I felt as well as I did before it started.

**Rose:** It didn't seem appropriate that the toast should include my successfully locating and ordering a pepper mill on the internet, which was my achievement for the day!

**Rose:** I guess it's that "other people" factor again – I can think of little achievements in my everyday life but they just don't measure up when I set them in the context of the wider world.

**Rose:** I can't even do this simple project, but it's trying to get an overview of how you, how all those components fit together my brain just couldn't do it.

### Containing Illness

**Separating self from illness**

(being controlled by illness/body)

**Margaret:** And the other side of it is that because you're used to feeling tired you think you're not that tired and suddenly you wake up and it's three o'clock in the morning and it's the weirdest thing it's like sleep's snuck up on you.

**Margaret:** It's one of these sneaky viruses that get inside your cells and then uses the cells to hide inside.

**Emily:** So you don't know which, in a way you regard CFS as being a false layer on top of everything.

**Emily:** Find this a really big problem, that people think you're just unreliable and well you are but through, through no fault of your own.

**Emily:** I suppose it doesn't really have a huge impact because you know that you're just feeling so unwell that there's no two ways about you going out so you don't have a choice and therefore you don't feel particularly guilty about it.

**Emily:** Don't know why really because I'm not a particularly socially anxious person um it was like my body was saying I can't handle the extra thought processes that have to go on in order to deal with having people around um...and it got worse and worse from that point to being any time I was out of my house going into feeling very anxious and it being like a phobia becoming akin to agoraphobia and then um.

**Rose:** You do have to tailor it to what you are capable of and not pretend that the ME doesn't go in the suitcase so it's not an issue.

**Rose:** I guess my body and I are partners in adversity in a way. I think my body is just fine...
(though maybe not aesthetically!), it's just the ME that makes it misbehave.

**Rose:** I think it probably is, yeah, yeah, I think it probably is, I just wish I could compartmentalise this so it didn't impinge on other people, you know, that's, that's the frustrating bit...if I was living in a vacuum I could get on with it and deal with it so much better, but it's other people that make it difficult.

**Sam:** But I think it is almost like my body's warning sign that you know, you're getting tired now um, slow down kind of thing.

**Margaret:** And I do feel at times that [reaches for another tissue but there is none left], you should have let me get my box![laughs] umm that you know that if I hadn't have got the Chronic Fatigue, life would have been very, very different, that I know that I wouldn't have been getting the grief I'm getting at the moment.

**Emily:** I could have made a serious contribution to the world and none of it happened because I never had the chance because of this stupid illness.

**Rose:** So it's, it's this thing that follows me about all the time, a separate entity like a dark cloud or something, following me.

**Rose:** Yes I think I think of it as this annoying separate entity that follows me around and governs my life and makes me a different person from the person I want to be.

**Rose:** When various bits of it hurt or refuse to function properly, I don't get cross with my body, I get cross with the ME, which is an extraneous entity.

**Rose:** Having said that, when my fingers won't work properly or it hurts to life my arms and brush my hair, it's the ME's fault.

**Not separating self and illness**

**Emily:** Me having CFS'. So you don't know which, in a way you regard CFS as being a false layer on top of everything and that it's difficult to know what genuine changes and yet it's silly because CFS isn't false. CFS is making you who you are so any change is valid and genuine.

**Rose:** But when my brain won't focus, I am much more likely to blame myself and think I should be able to control it better.

**Interviewer:** You, or are they something separate [referring to illness]?

**Peter:** Well they are me, they are what forms the basis of my life, um I can't do things because...
Keeping others unaware

Lucy: I mean my mum will always call me and say how are you feeling today and I'll always say 'I feel fine' even if I'm not because I don't really want to, you can say you're ill fifty million times and it doesn't change the situation.

Lucy: For them and also because I don't really sometimes I just don't want to go into it, you know I don't want to go into it.

Interviewer: What would 'going into it' be like?

Lucy: For me I suppose it would just be admitting how I feel.

Interviewer: It sounds like that's a hard thing to do, to admit to those feelings?

Lucy: Yeah it's you know, like saying no I don't feel very well, no I don't, I feel dizzy, I feel tired, I feel sick and you know, I don't feel I can't do anything today and I don't want to say that I want to say 'Yeah I'm fine, I'm OK, how are you? And end the conversation and just say huhh [sighs].

Lucy: It would just be really repetitive, it would just be so repetitive, it really would, honestly it would, I don't want that to be my everyday conversation, I'd rather not you know. I'd rather try to take my mind off of the things and like to talk about my thoughts and feelings all the time and when I'm with other people it's nice because I don't socialise that much so when I do I don't want to, it to be centred around that.

Lucy: And they didn't know what was going on and I didn't know what to tell them 'cos I didn't have a diagnosis so I went back to work part time for a few months and um I ended up actually using my annual leave to on top of that, to break it up even more, which probably looked incredibly strange so I was working maybe 1 or 2 days a week or something like that so I was desperately trying to not appear to be too sick.

Rose: But nor do I want to explain that I'm unable to work due to illness etcetera um.

Rose: Yeah 'cos I think yeah because people with illnesses are boring so I tend to try and conceal it when I'm out in the big wide world and then moan endlessly about it to my husband and my daughter.

Rose: Because I don't want to alienate people by making them think I'm trying to make them feel sorry for me.

Sam: But it's, it's er quite hard communicating to people that don't know the whole truth.
Sam: But I thought I just, I don't, I just can't be bothered to explain why I'm off.

Sam: No because they don't kind of know the full extent of it.

Sam: He called me when I was really tired and I just couldn't be bothered to explain.

Sam: I don't know, I suppose it's a bit like now I haven't told people I'm off um so I suppose I find it very difficult being open with people, I'm not very good at sharing my problems.

Sam: So somewhere in the depths of [location] is on my record that I might at some point need more time off, you know, might have more sick leave than normal but the school you know...the people I actually worked with didn't know so I suppose communication is probably one of my down sides um, I think in a way it's because you don't want people to perceive you any differently.

Sam: It's me again [laughs] thinking they might think that I'm not up to, you know not up to doing my job.

Sam: Me[laughs] me wanting to believe that I'm completely better I suppose.[discussing reasons for non-disclosure].

Sam: [interjects] I'm admitting it to myself yeah because at the end of the day my true friends will understand so but yeah, I think it's me.

Sam: Um, it's almost like admitting defeat um because I'd come so, so far and you know, but I know that I can, you know [indecipherable].

Sam: But it's probably coming to terms with the truth myself and it's the same with my friends yeah I think it's easier to be honest and open with the people that saw me when I was very ill when I was at University because you couldn't help but know then, but it's harder with people with people that have only known me since I've been really kind of fairly you know it hasn't affected my lifestyle to such a great extent.

Sam: It's a bit kind of I mean it's such a it's a bit of an unknown kind of thing and it's hard to explain you know, oh I get a bit tired sometimes well everyone gets tired sometimes um it's, it's quite hard to actually get a grasp of what's actually wrong whereas kind of my [names place of work] and University friends they'd know that if I'd gone out for somebody's birthday in the evening I'd go out and I'd drink water all night and I probably would have been in bed for half the day so I could have gone out for a couple of hours you know I used to say I could do one thing a day when I was very ill and I used to

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Seeking to be open

Rose: But on the other hand I guess if no-body with ME ever talked about the situation then no-body ever will understand so it's a tricky one.

Peter: Well I've learnt not to with other people you know a brief history would take ten seconds 'cos I you know, I working down the [name] centre everyone's ill and no-one wants to hear your problems for any length of time and it's not necessary because they all need cheering up as well so you know it's just you know my problem is when I meet a new person I need them to know that I have a problem.

Sam: I said no, tell her the truth [voice wavers] you know tell her I'm exhausted, I've been signed off, because it might help them understand you know a few weeks ago so they were fine about it so I think partly I've got to manage that a bit you know...how I can kind of change people's perceptions if they understand a bit more maybe.

Controlling Illness

Controlling symptoms through external agent

Margaret: In fact, I've since learnt that actually mental effort is more depleting in terms of energy than physical. In terms of actual the energy that it uses, in terms of the sugars that you use. So one of the things that happens is that if you're tired and you need to do stuff, you eat because you learn that is a good way to give yourself and instant boost.

Margaret: Yeah and I think I must have put on um 4 stone over the 9 years I've had Chronic Fatigue because it's, you don't eat the exact amount you need, you tend to just, you eat to get a burst of energy from the sugar and then if it, it helps, of course you get the full fat afterwards, which everybody gets, it happens to everybody if you eat you then get, you're blood sugar's go down and you start feeling that you need to do it again. But I've really noticed it, if I'm tired, particularly in the evening, um I'll eat, even if I'm not hungry, I'll eat...Simply because I know it will give me the energy to be able to keep functioning.

Margaret: I got better, I had this treatment which was [names specialist treatment] in nature um and there's no question that the virus level drops substantially.

Lucy: Um, my family have been great a great
support and my doctor prescribed an antidepressant which helped with the anxiety, because I did have really bad anxiety attacks um for quite a long time actually.

Jim: Well I try to er change my diet a bit you know I try to um ‘cos you read different things all over the place about it um ‘cos cheese I’d have cheese everyday of the week, now I try and have cheese at the weekend as a treat sort of thing ‘cos I read somewhere that someone was put on a diet which didn’t involve cheese and I try to have sort of yoghurt, try to put some healthy you know fruit and veg stuff into my body...um trying to do what I can do you know for myself drink less, eat better.

Peter: And um they diagnosed, the doctor had already said it was probably [gives a now retracted diagnosis] um and he put me onto amphetamines.

Peter: I’ve tried homeopathy, the only thing that really works.

Sam: Take lots of vitamin C, try anything I can.

Sam: By this stage the GP had already referred me to like a general a um some consultant practitioner at the hospital and I went there and he screened my blood for everything and I was low in B12 um which can make your muscles tired and weak as well so now I have B12 injections as well.

Sam: So at least you know, it might be a very minor part but at least that’s another thing that I can control and if, all it needs is an injection once a month then that’s fine [laughs] so I suppose you know I’m very aware of that as well.

Emily: it’s yet another example of me having to be careful of what I expose myself to because it things like that feelings of there’s certain TV programmes I can’t watch that deal with altered states of perception or people suffering, war, um I have to make sure that I don’t watch those as well so I constantly have to monitor what I am exposing myself to at the moment.

Emily: Being positive all the time, trying to find every silver lining is good but you are ignoring a very powerful feeling which perhaps will find an outlet in ways that are more destructive than you’d have been with in the first place.

Emily: And you just have to, you have to actually put so much mental energy and effort into keeping your thinking positive that it actually uses up you’re energy and so you feel more tired and so you can’t do as much and it gets into this huge vicious circle.
Giving self permission to express emotion

Emily: It is difficult to ignore um, it's probably there under the surface all the time but you get very good at learning mental strategies to block it so that, every time you start thinking those thoughts you go and distract yourself or just literally just block them and say 'no I'm not going to think about that' but it means that you are constantly running from it.

Lucy: I'd rather try to take my mind off of the things and like to talk about my thoughts and feelings all the time.

Peter: I mean you know, I quite enjoy the television occasionally I don’t like watching films, I watch um you know the nature things, anything that's got emotion in it I just can't handle um.

Peter: So it, it could be, it could be locked in there somewhere um but I find anything, even on the radio if I'm listening to a play and it starts getting emotional I just record over it um.

Emily: Expressing doubts, yeah, that would be probably be one of the things I would recommend to anybody dealing with illness is yeah, be look for the positive things, but make sure that you devote a little bit of time each week to really vocalising all of those doubts and negative stuff to someone maybe who you trust and who you trust not to get scared by you expressing those negative things.

Emily: So perhaps if you are a long term ill person you actually need to embrace thinking about these fears and accept that sometimes you are going to feel negative and have the, have a safe environment in which to discuss that and not try and just ignore it um, being positive all the time, trying to find every silver lining is good but you are ignoring very powerful feelings which perhaps will find an outlet in ways that are more destructive than you’d have been with in the first place.

INTEGRATION

Accommodating illness within pre-illness activities

Margaret: And then if you don’t rest then you’re mental abilities diminish, so you haven’t any health, even if you’re physically OK, you’re mentally just flat out, you can’t put it together. That’s why I started doing craft because although it’s a mental thing, it’s using the other side of the brain and it doesn’t, the critical faculty isn’t there?

Margaret: I love to teach. I absolutely love it
um... that hasn't changed um it's really funny even though I'm not well and I can't do, teach what I used to teach I find myself teaching friends of mine who are foreign how to speak English properly.

Margaret: So you've got to find something that you can dip in and out of both in terms of the community and in terms of the functions actually doing it and so many disabled people do it.

Jim: Oh yeah just normal going and having a beer with the lads, the boys always come over here every other week, they used to be in their boys football teams go and watch that um but towards the end, when I first got this my youngest boy was still doing football and I used to drive him there, but quite often I'd have to sit in the car and watch it whereas I used to get up and walk around and then I started talking a chair and folding chair in the thing, sit behind one of the goals and watch him from there, you can still, you can still um get involved.

Jim: Yeah it's about having to adapt do things slightly different um, you know I'm going shopping with [names partner] I always go food shopping with [names partner] and she pushes the trolley 'cos it tires me out.

Jim: It is just a matter of thinking about it and changing you're ways a bit.

Peter: Well about I'm trying to remember at this point about 14 years ago I found I couldn't read um I used to read books, you know go to bed and read a chapter um I got to the stage where I couldn't absorb anything because the brain started hurting and the eyes started hurting and so um I, I, I did a lot of recording of plays on the radio onto audio tapes and erm when I had a free view aerial installed last June it means now that I can get BBC7 and Oneword which are books and plays um and I find it difficult now to fit everything in.

Rose: Or example I phone my mum every day because she was bereaved [X] months ago and she's having a hard time so you know I sort of do a few jobs and then I think you know I can lie down and ring her or I can lie down and read the post or something like that so I don't feel like the time is totally wasted and frustrating.

Rose: And then, gradually, gradually, gradually, that got easier and I thought well there are other jobs I can do and then I quite looked forward to the thought that I could do something that would be far less demanding, far less hassle, I could really get into this and then I think it was for me in the last 6months to a year that I sort of realised that well maybe I'm never going to have a job again, I suppose it's also I, I've tried a couple of forays into volunteer work.
Rose: I still cast around desperately in my mind thinking what kind of volunteer work is there that I could do that would get me with people, 'cos I don't want to do anything that keeps me in the house using my energy at home because I don't have that much energy for being with people anyway so I want something that's to do with people but something that is totally flexible so that if I'm not well enough I can phone up and not do it that day and it doesn't upset anybody.

Rose: So I felt I needed to abandon that which was a great pity because I felt I really enjoyed it and I felt I was being useful, that's the important thing to me to feel useful in the world and I did feel useful.

Rose: But I didn't have to do anything for anybody else I could be ill and I wasn't inconveniencing anyone including [names husband] because he was happy just to read his books or sit in the sun whatever and when we went out we spent a lot of time just sitting on the beach which would normally be an anathema to me but they were busy beaches with lots of um surfers and you know people doing all sorts of stuff so there was lots of watch and it was a really successful holiday.

Emily: I've had to adjust my expectation levels of myself so much that yeah.

Jim: I've got a partner who goes to work full time and she comes home here and tries to do the house work you know everything you just feel a bit like er on a loose whatever, you know you can't contribute as you would like to and she tells me not to worry about it and all that but it does bother me a bit so I try and do like little bits and pieces like say like the washing up, bits of cooking anything I can really, so I'll go for a walk round the block, I'll try and potter around in the garden 'cos that hedge has got to be cut this week and I borrowed the hedge trimmers off my brother in law and I'll have a go it might take me ten goes but I'm not.

Jim: I might have a go at doing a bit of polishing now and again but she tells me not to bother you know but I know having her around makes it so much easier for me er but she works shift work like today she's doing 2.30 till 10.30 and then I'll have to go into [names location] to pick her up.

Jim: I know you have to lower you're standards you know because you can't live like you did...you can't keep you garden up as you did before or your housework you know.

Jim: And you're not able to join in with it all and I accept it more that I can't do that so it's...
stupid me trying to do it where as in the early
days perhaps I would have tried and then
knocked myself out you know, but I've realised
now that it's stupid to try and do that, just accept
it go round and see him and bring him a bottle of
wine or something you don't change it.

Sam: Um, it hasn't well like I say it hasn't been
so much of a huge problem and I used to be
really bad about coming home and just keeping
working you know they give you a lap top and
you come home from [names place of work] and
you keep working and um and I'm much, much
better at not working in the evening you know
not working so much anymore and I think that's
just part of the experience as well um.

Margaret: Right, well [pause] the kind of
person I am, I'm the kind of person who likes to
do a lot of things, you know I've always got
plans and intentions and taking the course this
summer has taught me that I can go a certain
amount of things but I have to plan for quiet
times beforehand and after in order to recuperate
from doing something that I really, really liked,
um, so I try to do that, of course nobody's
perfect and life isn't like that, you can't always
plan that you are not going to have a busy week
but you can try to minimise it at least every other
day.

Margaret: I plan the activities and I try and fit
the others stuff in around it.

Jim: 'cos she's not she's having driving lessons
at the minutes 'cos she doesn't drive so she gets
concerned about that, that it's unfair on me and
all that, but everything she does for me it's a
small thing I can rest up like I say to her if I
know I've got to come out at 10.15, then I just
rest and then come out it's only half hour and
then I can be in bed.

Jim: Um, I want to have a contribution
somewhere you know... she does so much for me
a small thing I said to drive to [names
location] and bring her back er no she's good as
gold.

Rose: It's very frustrating because um you have
to try and manage those peaks and troughs
around the rest of the world so for example um
I've been learning Italian and the only class that
I can now find that's at my level is on a [names
date and time] in [names location] in the evening
which is a disastrous time for me.

Rose: And in order to be able to go to that class
I have to spend all day Tuesday forcing myself
to do nothing.....I have to cook the meal in the
morning and put it in the slow cooker so that I
have absolutely no food preparation to do before
I go um so all I have to do is spoon some out

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Rose: And he gets to do that and um socially I mean having people round for dinner is so difficult because as I’ve told you by the time I’ve cooked I’m a wreck and that’s cooking a simple meal so we now try to work on the idea of maybe him learning to cook so that maybe he can cook and I can talk.

Sam: I work, if I’ve got a lot on I’ll work hard during the week so I don’t work during the weekend as well so that was partly one of...so that was like the first step really to me kind of trying to get a bit more of a balance you know sort of rest, relaxation.

Margaret: So I’m trying, I’m doing things that are more fun.

Lucy: Um, I think, probably appreciating things more, I think has definitely been something, just little things really.

Lucy: I suppose I’ve changed maybe I’m more patient with other people than I am with myself. I think I probably am more patient um and I think I probably take more time to listen to other people than I used to although I always thought I did. I think I do now maybe it’s because I have so much time that I’m not using productively that I want to maybe that’s kind of the reason why.

Rose: Um definitely spending time with my family has been a really important one and I think also it’s made me more, more thoughtful about other people’s predicaments.

Jim: Nah if I’d have still been at work I’d have just carried on as I say I’d have carried on in that job until I was 60 and [partner] works in a [gives profession] sort of situation um she [explains role] and obviously talking to her about has opened my eyes ‘cos you don’t realise all that’s going on out there.

Peter: I suddenly felt that I, I, I should be proud of what I’ve achieved in 18 years because um I’m not a dredge on society OK I get benefit but um you know I help um I’m a nice person. I like to think I’m a nice person um I don’t live in a shambles and everything’s messy I’ve achieved like the [names club]...I’ve achieved a lot so the only answer I can give you is that I’m proud of what I’ve achieved.

Sam: Hopefully my life might be more positive as a result because hopefully I’ll have a better quality of life um because I absolutely would
have gone down that road and would have burnt out at some point.

Sam: I think I’m far more aware of other people and how things are gonna yeah how things affect other people and then I suppose in a way I’ve always been fairly good at kind of understanding but I think. I understand more how can something can affect well different things affect different people and how obviously if it’s not something physical but it can how it can still affect people tremendously you know my head teacher’s dad has kind of only go weeks left to live and can imagine that she must feel there’s nothing physically wrong with her but I can imagine you know how her body must feel at the moment I can kind of think I can empathise more um and I think, I think just generally kind of the value of health.

Building new roles/interests compatible with illness

Margaret: If you wake up at 2 in the morning because you fell asleep at 10 and you can’t go back to sleep you’ve got something that you can do that doesn’t interfere with anybody, it doesn’t make too much noise um and you know you can do it, until you are ready to go back to sleep. It fits in brilliantly with someone who has Chronic Fatigue.

Margaret: But you get to the point where you’re so bored, you know of the endless repeats on television and even with [names a digital TV company] you still get endless repeats at various times, so I started looking around and I saw some craft programmes and I started watching them and I realised I could do that and I thought I was prepared to invest the time in learning it because I realised, if you don’t feel like doing it, then you just don’t. It’s not something that, you know it’s not boxed, when you’re an academic it comes in a box, you know you have to do a certain number of hours, you have a certain amount of admin and a certain amount of marking, a certain amount of lecturing a certain amount of seminars. You don’t get to pick and choose, whether you turn up on the day when the students are there. It’s not like that with craft. If you don’t feel like doing it, you just don’t.

Emily: CFS has given me a really much bigger appreciation of being able to do the little things in life and I tend to get quite a lot of joy from small things.

Emily: The other thing that’s probably changed
and had to change quite rapidly because of the CFS was that you only get a small amount of time in the day when you can have people over, you're friends see your friends because you only have a certain amount of energy which means that you get really good at tuning into people quickly because you know you've only got a very limited time with them you've got to quickly get on their wavelength in order to get some really good conversation going um but that's something that's quite useful.

Lucy: Having the freedom to go out to the shops, go shopping in the supermarket, ironing some clothes, you know silly things like that, housework, um reading a book um going for a walk in the park, going to see a film, um meeting up with my friends for a meal, you know.

Lucy: I suppose I've changed maybe I'm more patient with other people than I am with myself. I think I probably am more patient and I think I probably take more time to listen to other people than I used to although I always thought I did I think I do now maybe it's because I have so much time that I'm not using productively that I want to maybe that's kind of the reason why.

Rose: I think I've fulfilled a function in being there for people to talk to you know when they've got difficulties I feel I serve a function for our two mothers and our two daughters and I would with my husband but he's quite a closed person so he doesn't talk about his problems um but I feel that is a useful function I have in my life that I can't do lots of physical stuff but I can listen and sympathise and so on.

Rose: I thought well I didn't fit in anywhere and I'd go to adult education classes and everybody was retired except me and you know I felt such an odd ball and that really added to this sense of not having an identity anymore because I'd given up work but now I feel I'm sort of perhaps working my way into perhaps gaining an identity again as a retired woman, you know perhaps I'm allowed to be that.

Jim: Quiet um I've become interested in other things like the bird watching.

Peter: Well I think there's such a such a demand that um you drift into it, one of the hardest things, one of the disappointments I had, when I, when I became unemployed I'd been living here for 10, 8 or 10 years and there's a lot of elderly people around um and I discovered, I hadn't really thought about it before then...yes I had because there were three elderly spinster sisters that lived over there and once they got to know me...once they realised I was a kind person, they asked me to do little jobs they wanted to pay me you know um but I discovered that old people don't have jobs done because they are frightened of having people in the

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house, strangers in the house and I, there'd have been a wealth of work around if I'd had the strength to do it because I'd started doing jobs for people not just in the close but on the estate and then you know your reputation gets passed on to other older people their friends.

**Sam:** Which didn't do my back any favours either so at the end of my time off I had, I decided to not go back and I decided that I quite wanted to do [names profession] and it was something I'd been thinking about for a while before anyway so. I went, before I handed my notice in I did manage to get an interview on a [names course] and kind of thought that, that

**Sam:** When I can afford it um I think the nature of my job that I have 6 weeks or never more than 8 weeks to keep going that does help because I know that there's a break in sight as well and quite often by any of the holidays I need it um and it also means that kind of like the last week or two if stuff needs doing I can just say sod it I'm gonna leave it and I'll do it another.

**Sam:** I suppose my change in jobs also made me see things differently you know couldn't be more different and the jobs about different things and I think partly one of the reasons I left my last job was no-one actually enjoyed doing it um everyone bitched and moaned about it but if you stayed there long enough you just got stuck in the rut you just got used to earning really good money and you got to the point where you couldn't actually afford to leave because you'd got yourself such a big mortgage and the lifestyle to match it and I didn't want to get stuck in that rut so I suppose in a way I saw the light early, early enough to do something about it.
APPENDIX 14

(Quotations Corresponding to the Major Category of: Willingness to Contemplate the Future)
Willingness to Contemplate the Future: Associated categories, sub-categories and selected quotes.

<table>
<thead>
<tr>
<th>MAJOR CATEGORY</th>
<th>SUB-CATEGORIES</th>
<th>SUPPORTING QUOTES</th>
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<tbody>
<tr>
<td>Assessing the Capacity to Enact the Desired Future</td>
<td>Difficulty contemplating the future</td>
<td>Margaret: As I said, I think you stop planning that kind of distance.</td>
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<td>Margaret: Well, I mean the thing is that you don’t tend to think of in terms of time. I don’t think gosh by two years time I must be doing this</td>
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<td>Interviewer: Is there any time when thinking about the future isn’t associated with those feelings of pressure or is it always like that?</td>
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<td>Lucy: I think it’s always like that.</td>
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<td>Interviewer: And how do you get by, how do you manage with that?</td>
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<td>Lucy: It’s difficult because, I suppose I bury it a little bit I try to bury it a little bit. I don’t really talk about it though it’s not something I really want to talk about it.</td>
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<td>Interviewer: Does the burying it help?</td>
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<td>Lucy: It doesn’t really help, but I don’t see how it would help keep thinking about it...I don’t really see how that would help either.</td>
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<td>Lucy: I don’t really like to think about that actually. No I don’t really want to think about that it would be very hard.</td>
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<td>Rose: I think it’s more often pushed to the back of my mind.</td>
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<td>Peter: Um well I don’t think about the future…… I don’t know what I’d think about.</td>
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<tr>
<td>Conflict between current existence and future plans</td>
<td>Jim: I’m sorry, I can’t sort of think too far ahead.</td>
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<td>Jim: Which is a big step as well ‘cos I mean {names wife} should be here more ‘cos she’s sort of running two properties at the moment the flat she shares with her boys and this where she spends most of her time so that’s a step in the right direction...that’s another sort of to settle me down a little bit but I just feel I can’t sort of look too far into the future because I don’t know how I’m going to feel.</td>
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<td>Margaret: but I don’t because I feel I can’t rely on myself to be well enough to give the job that I need. I mean I was really impressed, there are</td>
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people who are at the session, that young girl who had [names a different condition], she’s working and you know and I’m really impressed. I mean the problem I have is that I don’t really want to go and work in a supermarket or you know, whatever, I don’t think I can give an academic job what it’s due, because if I didn’t feel immensely alert all the day, how the hell can I [describes aspect of previous role], you know, you have to be alert, you have your goals and you know.

Margaret: Well, it fits crap doesn’t it [laughs] it absolutely fits crap. I mean, I feel like, you know, I have all these great ideas and I, I can’t put them into execution and you know, I feel like I need two right hand men women, whatever, to do all the leg work, but... I don’t have them...all I have is me.

Emily: I just thought of something that I possibly...I definitely would have done more of if I hadn’t have had CFS which was that as I touched on earlier I was a very, very active kid and was a member of [names sports team] athletic club and did Gymnastics and um and I played tennis and I really probably would have wanted to take the tennis to quite a high level and that all had to go and that’s actually one of the things I’m saddest about is losing those...losing the hope of being able to actually compete in a physical sport like that which I enjoyed so much as a kid.

Emily: I can see myself at the end of my life having, being on my death bed perhaps, old grandma or whatever and saying I could have made so much of my life I could have done the things that I wanted to...I could have made a serious contribution to the world and none of it happened because I never had the chance because of this stupid illness.

Lucy: Um probably because err, I don’t know. I suppose because the choice isn’t quite sort of there you know it’s limited because of my situation perhaps if you think...if somebody says to you, you can’t have a child you want it even more I don’t know if that makes sense to you, perhaps it’s that feeling.

Lucy: Yes definitely because I’m quite sort of scared that because of my situation I might not be able to, so I want it probably more, I would say...

Lucy: But it’s just like the choice has been slightly limited really yeah.

Lucy: Um the situation I am in right now um I don’t really see how I can do all those, I know I’d like to but I don’t really see how I could.

Lucy: It’s quite hard, it is quite hard...
um...because sometimes they feel unachievable so and like I said to you even though, I do.

Rose: I would never be able to work even if I wanted to work and that’s a, you know quite a strange realisation, because before I’d always thought my aim was always getting back into the work place, so it’s a bit of a funny feeling.

Rose: What is my future going to be and I really did feel down because as I say, this should be an idyllic life in one way because I’m being paid to stay home and do whatever I like you know my husband’s supporting me and you know it should be wonderful but it’s er, the reason I have got this freedom is because I’ve got this illness which, which, um you know prevents me from having the freedom I want.

Rose: People are always saying to me you should write a book you’re so good at writing you should write a book and It’s something I would have loved to have done in former years and I think now I’ve got all this time I could write a book because it doesn’t take any physical exertion but I just haven’t got the brain for it and it’s hard to make anyone around me understand that, that I can’t um, er.

Rose: That made me stop and think well you know, when’s my next achievement coming along, where am I going to find a vehicle for achievement, something to look towards.

Rose: No I don’t think so I mean hopes would be go travelling and see much more of the world and I’m reconciling myself to the fact that that is probably not going to happen.

Jim: [interjects] yeah it’s not what I’d normally want to do um I don’t like it if people let me down and not being able to guarantee that plot of time you know why would someone want to employ me that can’t ’cos I wouldn’t want to employ someone that can’t guarantee they’re going to be their at certain hours, you just can’t.

Jim: If I could get back to work, I’d like to do driving ‘cos I’ve had all those years in the office I’d like to be out and about bit of freedom you know um yeah I often look at the old van drivers when I’m out and about thinking yeah I wouldn’t mind being able to do that, but I know I can’t because I don’t know how to no you can’t because I wouldn’t be able to lift the stuff for a start you know as it is, but that is my intention is to get back to work, I just don’t know when.

Jim: But as it’s been going lately you know I don’t feel like it nah...long term things have sort of gone out of reach really.
Influence of developmental stage

**Margaret:** Of course he's always busy and he complains a lot but um my age and the fact that I never did get the [qualification] are against me and I'm probably too old to do that now, so I'm trying, I'm doing things that are more fun.

**Margaret:** I want things and I would like to develop something in craft, right, to that aim I'm actually working on it um but the problem is, you know, if I had all my energy it would be easy, you know, it wouldn't be easy you know, nothing is easy if you want to make a success of something but it's like I went to the [names craft show venue] and there's these people there and I've seen them on the television, I know that they do one young lady, she must be in her 20's early thirties probably 20's, she was it's punishing she was, four day exhibition Thursday, Friday, Saturday, Sunday, that's killing, I mean one day for me is just going to wipe me out for a week but she did 4 days she was on the Tele yesterday-my! And I just thought, how does she do it? And of course she does it because she's one, you know, young and two, she's not ill.

**Emily:** Yeah I guess it does at almost such a basic level of my thinking that I almost don't realise it and I just catch myself thinking it sometimes that I can't go and assume that I'll be independent I have to to any plans that I make for the future I have to make sure that I'm near my parents, near people that care about me and I'd love to be so free of fear that I could quite happily just go off to some remote part of the world and feel happy in just setting up a life all by myself and there's no way I can contemplate that at the moment, because one I can't physically look after myself at the moment because I can't physically do shopping or um any sort of money and two I actually at the moment need the emotional support because I'm needing so much mental help from people to keep going.

**Lucy:** Umm I'd like to I want to start a family I definitely want to start a family I'd like to have children um and I'm worried that the longer this goes on the least likely it is that that will happen. I'd like to um meet somebody obviously first and um get that to work and um just travel a little bit maybe not necessarily in that um order.

**Lucy:** I don't know really it's just a feeling I guess you know, wanting to be a mother is just a feeling I don't know, not because someone else is doing it or, but not because that's what you do, because there was a time in my early twenties when that wasn't something I thought about really, it wasn't until my sort of mid twenties it was something I thought, yeah I might just start thinking about this now you know, I'm not going to do it right now but I'd like to it's something really considered really seriously.
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<th>Presence/absence of illness within the future</th>
<th>Illness as temporary</th>
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**Rose:** Um I think about that mostly in terms of family I worry about our mothers because they are not in good health and I know that at some stage they are going to become very dependent and I feel very concerned that... because I'm not working the assumption will be that I can care for them and I know that I can't and I feel that, that is likely to cause friction within the family, because it will be assumed that because I am at home I'll be available and there was a problem when [name's husband]'s mother went into hospital a few years ago and er her neighbour insisted that I go down and stay with her and she said oh you only have to be in the house, that's all you've got to do just be in the house and er you know at that stage of the ME it was too much even doing that, just having someone around who talked at me you know it was too difficult um so that's a pre-occupation.

**Rose:** And a big, big, big pre-occupation is that I'm very much looking forward to having grandchildren though I don't know when that will happen and I'm very concerned that I won't be able to cope with them because children are noisy and active and busy and er I did a family literacy group when I was working in fact several of them and they would have a crèche for the babies and if the babies got to noisy then the crèche workers would bring them... you know if they were babes in arms they would bring them into their mothers and if the mothers couldn't do their work holding a child they'd give me the babies to hold and I wasn't strong enough and I find it very distressing to think that I might not have the strength to cuddle my grandchildren, you know they'd be too heavy for me to walk around and hold them.

**Rose:** Because I'm realising that even if I do become fit enough to work, I'm quite an old lady so people might not actually want to employ me, particularly if I have a history of illness.

**Rose:** That, that is really going to bring the guilt thing to the fore because I shall feel like I should be looking after the children, because I've got all the time in the world but I'm not capable of doing it.

**Jim:** [names role and location] basically so I'd been there a long, long time I've got a lot of friends there and that's all sort of disappeared because it was always my sort of intention to work until I was 60, be able to retire on a reasonable pension and then go out and do some voluntary work or whatever, you know part-time work, but that's all been snatched away you know my pension has been frozen now until I'm
Lucy: you know, every, when I was ill, oh all the time I’m ill, I say to myself well it won’t be like this in a year’s time it will be different.

Lucy: I say to myself well it won’t be like this in a year’s time it will be different.

Jim: It would drive me mad I can’t afford to let myself think, I don’t know what I’m going to be like in six months time, a years time, hopefully I will be better so to speak.

Rose: I think the most important thing that I gained was um that um my way of dealing with it and to a certain extent still my way of dealing with it is to think that I’m going to wake up tomorrow and it will be gone.

Rose: And I had always thought before well I’ll be back at work soon.

Rose: Relatively recently I think ‘cos when I stopped work in [date] you know I thought I was just having 2 days off and then I was in bed for months and months and months and even then you know when I was in bed, I couldn’t get up, I couldn’t do anything and I still kept thinking to myself, oh next week I’ll be back at work, next week I’ll be back at work.

Rose: .. a bit of a Scarlet O’Hara really in that I, I just prefer to think oh well things might be different by then and then I dismiss it that way I think “oh well the ME will be gone tomorrow”.

Emily: Well the way that I hope the future would go would be that I’d get back to University in a year or two’s time, do so much more stuff that anybody, that any Uni student would be doing that I would feel mentally really safely far away from all the bad stuff that’s gone on all the anxiety disorder and the general illness, that I could forget all that and just be normal and just go and lead a normal life.

Emily: I don’t want my entire life to be about compensating for my bad experiences of suffering and so in order to maintain a more rounded life I need to things that interest me and that I would have been doing if it hadn’t have been for me having CFS and anxiety

Jim: Well, like I say I’m getting married next week which is a step in the right direction but I’d also like to get back to working, some sort of work even if it’s only part time.

Jim: but that is my intention is to get back to work, I just don’t know when.

Lucy: Start to go back to work and I’d like to go back to work and start part-time and that...
Seeing fulfilment of future plans as dependent upon recovery

would be the first thing I'd like to do

Margaret: It still feels like it's not back at the top where it was um what did my Doctor say um, the specialist said that basically he operates I think on he hopes to get more than 80% but I think he's looking at an 80% achievement and at the very best 95%.

Margaret: If I had all my energy it would be easy, you know, it wouldn't be easy you know, nothing is easy [talking about capacity to enact future goals].

Margaret: And if you, you need sustained effort to make a success of anything and it's very difficult saying that. [talking about future goals].

Margaret: I mean I'll be lucky if I get the craft things going, but even that isn't, it isn't what I would have wanted, it's a second best solution.

Margaret: Well I don't know I've not exactly done anything yet in craft I’ve not actually changed anything. I wanted to set up a co-operative in [names location] for crafters. I completely failed to do it, partly because I don’t have the energy to do it.

Margaret: How would I need to be, I'd need to wake up everyday with you know the joys of spring wouldn't I feeling full of energy and knowing that if I push myself today, it isn't going to effect me for the next two days or even three, it's like that is really key, really, really key.

Emily: And I really would like to have achieved something really done something that leaves a positive mark on the world by the end of my life. What I fear my future will be like might be that I’m stuck just being on and off ill all the time and never really reaching my potential.

Emily: And I can't actually intermit a second time you can only do it once at [names location] so you have to be really sure that you are well enough to go back and at the moment I am no where near it.

Lucy: Um well I’d need to be well again, I’d need to be as well as I was before all of this started...I’d need to be at least 99% if not 100% [discussing capacity to enact future plans].

Lucy: Because I feel limited, I’m limited by um how much I can achieve physically and because I’m not able to achieve that much physically.

Jim: But I would like to go and do part time work but the problem is with this illness, I don’t know when I’m going to get a good part on what
day. I can’t guarantee to someone that I’m going to be able to work 10 till 2 or 12 till 2 whatever it is because it’s not like that so it puts you off.

**Rose:** I think back with such fondness to when the children were little and the things that we did together and I so look forward to doing things like that with my grandchildren and if I was too tired and it was all too much then, that would be so hard.

**Emily:** ...but maintaining the lessons that I’ve learnt from the CFS um and maybe putting those lessons into practice, whether it’s actually doing it professionally or in some way being able to use those things in your job and helping other people or whether it’s just that you use them in your life with people that you know that you can just make, maybe make things easier for them, because of the things that you’ve learnt from dealing with hardship um that’s how I’d like it to go and I really would like to have achieved something...really done something that leaves a positive mark on the world by the end of my life.

**Emily:** It would feel really pointless to have gone through all of this and then to have not used the things that have come out of it there’d be, you know you’d think ‘OK well why have I gone through that then’ so I definitely would want to use them I would probably consider doing charity work in some form at some point in my life um I already um was doing some work for um [names organisation] in their centre and doing work for [names organisation] in their shop and I can’t seeing myself enjoying a job where I feel that it’s meaningless that it’s not having a positive impact on people’s lives um in a strong way um I see myself doing making contributions to science or people’s understanding of science and actually I feel like that’s really positive because it’s not directly connected to my sense of having to make people’s lives better.

**Rose:** I’ve thought about it a lot more lately I think my father dying six months ago he died very suddenly and that I guess makes everybody take stock of their lives and stop and think about the fact that life can change dramatically either for you or the people around you and so you start thinking about things I mean even to the extent that um er my husband is never ill but he has had a problem with his feet lately and er I was thinking what would we do if he couldn’t walk around, if he couldn’t drive (‘cos I can’t drive very far), you know how are we going to cope if he’s not this wonderful stalwart that he is now um he’s a great support to me but if he got ill, how would I handle that if he needed nursing and I couldn’t deal with it that would be terrible you know ‘cos he’s given me so much that I would want to give it back again so you know
maybe that seems a crazy thing to think about on an everyday basis but I think it’s just because my father died you start thinking that you know life can be things can hit you out of no-where. [discussing reasons for shift towards thinking about illness in the future]

Jim: Yeah we were even talking about fostering you know being foster parents um ’cos both of us our children are more or less off our hands, my youngest is [names age] he actually lives with his mum but he comes here every other weekend type of thing, so we have actually looked at that um but the first bloke we went to recommended that we should be married..

Interviewer: Is that something that you feel you could do kind of at the moment?
Jim: Well if [partner] was here as the main carer and I was just like the back up then yeah we probably could do it as a pair...it won’t be easy we know that but that’s part of the enjoyment of it or that’s something that’s hopefully in the pipeline.

Interviewer: Is that something you, you would have thought about doing before?
Jim: Nah if I’d have still been at work I’d have just carried on as I say I’d have carried on in that job until I was 60 and [partner] works in a care sort of situation um she [explains role] and obviously talking to her about...has opened my eyes ‘cos you don’t realise all that’s going on out there and we thought well we’re in quite a nice position to be able to do something about it

Peter: And it’s just got so ‘cosy I don’t want to go anywhere else.

Peter: Uh I don’t want it to sound ungrateful but, I’ve got nothing to look forward to I don’t think um I’ve got no complaints [discussing the future].

Peter: Well it’s it comes soon enough you know being incapable or not being able to get out happens and one of the things one of the inspirations I get is there’s a lady that goes to the community centre she’s a [gives age] and she’s in a wheelchair but she’s had [gives identifying information] since she was 25 and she’s staggering you know [laughs] that wasn’t meant to be funny she can walk but she, she’s in a wheel chair when she’s moved around obviously but she’s so happy.

Peter: I mean, I watch them I watch the travel programmes and the country file on a Sunday is fabulous because um, because I don’t travel that’s my travelling um but I’m never going to do there to these places that they make look so fantastic and I, it doesn’t worry me so much.

Sam: It’s been OK and I think talking about the futures kind of a good thing because it’s not
dwelling on the past and then, that's more what I want to do and then I want to think about my future and how I can although you can't guarantee yourself a great positive future but how I can you know help myself to make it as positive and happy as I can. So that's a good thing thinking about the future more, rather than thinking about the past and er I was I'm always easily moved to tears anyway I just seem to be particularly bad at the moment.

Sam: I think I've probably always done the sensible um like I never went travelling after Uni which I wanted to do I suppose partly it was health wise but [partner] and I brought our last house instead which was the sensible thing to do but I kind of wish I had just gone even if it was just for two like months um so yeah things like that and whilst I know that I could go off for a summer holiday and [partner] wouldn't mind you know [partner] wouldn't stop me and he's always said you know that if I want to go to Australia then I can go for six weeks and he can come out for the two weeks for you know the two weeks that he's allowed off type thing it's the fact that I don't really want to do it without him now so yeah.

Sam: I suppose that's getting to the age where we might want children but I'm, I'm a bit undecided on that point at the moment so I think if you'd asked if you'd asked me five years ago where I'd be now I'd have thought I would have thought for sure yeah we'll be married we might have a baby but and now I just think well I'm not really sure it's um I quite like my life not having to think about other people it's just the two of us.

Sam: He [partner] knows me absolutely inside out um but he er he's kind of like my rock at the moment really but I think I'm definitely in the place now where I can go forwards, I'm definitely determined to but you know I've just I want it to be a positive time now um.

Sam: Um in a way it's quite positive because you know I can do something about it and, and er I know talking to my Nan yesterday who was going on about ancestors and I'm like I don't care about the past you know I don't care about these [names regional area] you know that I've never met but I worry about you know making the world a better place now and for the future you know I can do something I can do something about my own happiness for the future so in a way that's a positive thing but in a way it's a bit scary but then I suppose it's a bit scary for everyone because, you know.

Sam: Because...it's unknown...you never know what's going to be thrown at you um and you don't know how things will work out but I suppose it would be strange and a bit boring if you did so [talking about the future]
**Considering alternative futures**

Emily: Well the way that I *hope* the future would go would be that I'd get back to University in a year or two's time, do so much more stuff that anybody, that any Uni student would be doing. What I fear my future will be like might be that I'm stuck just being on and off ill all the time and never really reaching my potential.

Emily: And so sometimes it actually feels like inside you can physically feel two bits of you fighting um which is the hope versus the fear.

Lucy: My fears are um not being able to go back to work not being able to have children and my hopes are those as well.

Rose: Um most of the time I see this going on forever and yet at other times I still have the naïve little girl thing that it's going to be gone and I can never make up my mind which is the right attitude.

Margaret: I got better, I had this treatment which was [describes specialist treatment] in nature um and there's no question that the virus level drops substantially. [discussing reasons for re-engagement with pre-illness.

Lucy: Um, well, on a good day I just feel I've got a bit more freedom really, not that I physically do that much more I just feel a sense of more freedom, I can feel more optimistic and I can sort of think about things that I'd like to do you know in a more positive way, rather than thinking about things that I can't do.

Lucy: I don't want to, I still, you know like I said, when I have a good day, I still like to think about the things that I would like to do whether it's a job or an interest or you know I might see you know one of those holiday programmes on TV and think you know I'd really like to do that and think about it rather than I don't want to get into a situation where I just feel like I've given up and I just think well it's not ever happening I'm never going to be able to have kids or I'm never going to have a relationship.

Jim: We've met people that have had it for 20 years and have still got it and you sort of wonder which one am I going to be. It is yeah the uncertainty of not know how long am I going to be like this for but if Someone were to say to me tomorrow you're never going to get better, this is what you're life is going to be like till you die or

**Future plans influenced by shifting symptoms**

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something, perhaps you would just accept it and it's this not thinking that next week I might be alright.

Jim: If they said you're going to have it for the rest of you're life you could perhaps deal with it and say right this is it I'm not going to get better

Jim: I had picked up again and I was thinking to myself perhaps this is the start of and people were telling me again um I was walking better and even [partner] said you're walking faster um which is something I hadn't really noticed and I said oh that's good but now it's all sort of gone backwards again.

Rose: It's a mixture of good and bad really I mean it's good because then I start planning and thinking Oh I could do this and I could go there.

Rose: Nope it's something that I still do now as I say since Christmas it's been a er not so brilliant time but about two weeks ago I had two days when I could actually get on and do things and they had come immediately after a week of having lots of dizziness and when I'm really dizzy I have to lie down and I can't read, I can't listen to the radio I just need total sensory deprivation and um so it was grim and then I had these two days where I could get the house cleaned and I did a bit in the garden and I thought this is great this is wonderful and then it all fell apart again but during that time I was thinking oh the summers coming we will be able to go out for a picnic and go for walks you everything and it's just so nice when you can look forward to things you are going to be able to do.

Emily: Because I'm in one of those stuck situations again where I've just relapsed.

Emily: And this is just wasting time really, because I'm just waiting around.

Lucy: Um, at the moment things are just sort of stuck so they're not sort of any worse but they're not any better either.

Lucy: It's just I don't feel like I'm really improving I suppose at the moment as much, you know, as I'd want to although I try to be optimistic about it, you know I don't feel like I'm progressing, it's been since [gives date].

Lucy: Um really generally, I don't see my life as that great at the moment um because I, you know it's been [gives duration of illness] and in that time my life is sort of standing still.

Jim: Er I think I just take one day at a time really because I can't plan anything very much
Living in the present

too far in advance because you never know how
I'm going to feel but um I'm getting married
next week so that's a big step.

Jim: It's more or less as you go day by day.

Margaret: You asked me about how do I see
myself, you know, developing and I'm like, I'm
developing? I'm lucky to be able to stand still.

Jim: But as it's been going lately you know I
don't feel like it nah long term things have sort
of gone out of reach really.

Jim: So I say looking to the future is like now
really.

Jim: I don't mind but it's just difficult to
explain it the future is tomorrow or the rest of
the day.

Rose: It doesn't do does it to dwell on bad things
in the future it's more important to try and focus
on the present and live through what's
happening now.

Margaret: I don't think gosh by two years time
I must be doing this, you think I have these jobs.

Margaret: It is a goal but it is a job. For
example I have a job to do in this house. I've
got to get it back into some sort of order, tidy it
up. It feels like a never ending job there's things
I absolutely have to do, I have to keep the
kitchen table tidy. I have to cook dinner. I have
to feed the cats and I have to do maybe one or
two other things. Those are the 'have to's' and
then there's the huge long list of things that have
to be done eventually but don't necessarily have
to be done today and that's the list that's so hard
to break it down and make it smaller. It's really
tough to do that in fact it just gets longer, I think,
every, every day, every week it gets to be longer
and looks even bigger.

Margaret: It's because I don't have any plans
of what to become as a person. There's things
that I would like to do, I have plans for that.

Rose: It's just that so much of the week seems
to get taken up with trying to keep the
housework under control and trying to do the
shopping and do the cooking and you know I
have to use so much energy on the basic stuff
that there's not a lot of energy left over for other
things that might give me a sense of
achievement.

Peter: I mean I'm thinking about the future in
as much that I need and I can afford a new porch
door but that is like survival you know the mud
hut is falling down so I've got to make some
more mud um my bathroom is derelict and my
kitchen is derelict, I mean after finishing this my aim was to start on the bathroom my aim was to start on the bathroom and I can’t talk myself into it, it’s clean but it just needs tender loving care.

Peter: Oh it’s essentials um you know I’ve got a freezer I have the milk delivered I have a radio times delivered, I don’t need anything else um and I do need.

Waiting for Recovery

Emily: Because I’m just waiting around for me to get better to do the things that to just move my life on. And that brings up a huge amount of angst because if you’ve got um aspirations and you’ve had to just be so patient for so long you can be patient most of the time.

Emily: And I’m waiting to get better.

Emily: So again it’s just a waiting game and it’s the number of times you have to do this that can really get to you.

Emily: Um a bundle of enthusiasm for the future and potential that I want to, to explore and I’m just waiting and waiting

Jim: Hopefully I will be better so to speak.

Battling to keep hope alive

Emily: [laughs] So often I just feel completely torn between two extremes all the time my emotions always seem to be um both ends of the spectrum at the same time because you’re very optimistic and very fearful both at the same time because generally I am, I’m not somebody who’s prone to depression luckily um I’m quite a happy and very enthusiastic person, but, you can’t help but have fears when for [X] years things haven’t overall got a huge amount better and so sometimes it actually feels like inside you can physically feel two bits of you fighting, um which is the hope versus the fear.

Emily: I think you have to spend a lot of mental energy keeping the side that you don’t want to win in check and you have to put in so many little mental strategies to stop it getting too strong um...ways to ignore it or minimise it and concentrate on the hope side of the battle.

Emily: Pretty much yeah and I try and focus on the hope and ignore the fear...but then if you keep doing that, keep pushing it deep, deep down they you possible get it coming out in odd little ways.

Emily: There’s a lot of I mean just at the moment, there’s like an er inward battle with keeping hope.
| Lucy:  | I don’t want to get into a situation where I just feel like I’ve given up and I just think well...it’s not ever happening...I’m never going to be able to have kids or I’m never going to have a relationship, I don’t want to because that will just reassure everything it really would and I don’t want to go down that road I’ve nearly got down that road, I have, I think I probably did actually, I don’t know what a break down is but I think I probably did have a break down.  

Lucy: It’s quite hard, it is quite hard um...because sometimes they feel unachievable so and like I said to you even though, I do you know I don’t want to give up I don’t want to feel like it’s never going to happen and get into a situation where I just think, what’s the point.  

Lucy: I have done in the past when I’ve had when my symptoms have been really prolonged and I’ve not been able to see any realistic outcome then yes I have been there but um occasionally I do a little bit but I just try not to I try not to, because I don’t want to feel like that, because to me I’d be like that then I’ll never have anything I’ll never have you know a family or you know a job.  

Rose: But on the other hand I think if I never thought it’ll be gone in the future I’m not sure I could cope with such final knowledge I think I’d find it too depressing to deal with, so maybe I need to have that little bit of naivety and think oh it’s not going to be there for long. |
APPENDIX 15

(Development of Focussed Codes/Categories Interviews 1-3)
### Focussed Codes and Emerging Categories Identified Following Interview 1: Margaret

<table>
<thead>
<tr>
<th><strong>FOCUSED CODES</strong></th>
<th><strong>RESEARCHER CATEGORIES</strong></th>
<th><strong>EMERGING ABSTRACTED CATEGORIES</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>Receiving diagnosis</td>
<td>Uncertainty surrounding diagnosis</td>
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<tr>
<td>Pre-empting diagnosis</td>
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<tr>
<td>Questioning diagnosis</td>
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<tr>
<td>Disputing Diagnosis</td>
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<tr>
<td>Dismissing Diagnosis</td>
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<tr>
<td>Understanding diagnosis;</td>
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<tr>
<td>Accepting Diagnosis</td>
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<tr>
<td>Undergoing biological tests;</td>
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<tr>
<td>Accepting illness following biological explanation</td>
<td></td>
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</tr>
<tr>
<td>Experiencing infrequent better days</td>
<td>Uncertainty surrounding activity</td>
<td></td>
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<tr>
<td>Linking symptom fluctuations to seasonal changes</td>
<td></td>
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<tr>
<td>Predicting seasonal improvement in symptoms</td>
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<tr>
<td>Experiencing uncertainty; Experiencing improvement; Expressing uncertainty about prognosis</td>
<td>Uncertainty surrounding prognosis</td>
<td></td>
</tr>
<tr>
<td>Giving body a voice. Being controlled by the body Controlling the body with the mind. Separating body and mind</td>
<td>Separating body and self</td>
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<tr>
<td>Understanding illness biologically Understanding illness as incurable Attributing recovery to reduction in ‘biological markers’ of illness following treatment Evidencing biological account of recovery</td>
<td>Understanding illness biologically</td>
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<tr>
<td>Questioning personal motivations underlying current difficulties Questioning validity of</td>
<td>Questioning Illness</td>
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<table>
<thead>
<tr>
<th>Illness Experience</th>
<th>Exceeding limits</th>
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<tbody>
<tr>
<td>Pushing self to continue</td>
<td><strong>Exceeding limits</strong></td>
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<tr>
<td>Difficulty balancing rest/activity</td>
<td><strong>Exceeding limits</strong></td>
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<tr>
<td>Difficulty adhering to rest</td>
<td><strong>Exceeding limits</strong></td>
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<tr>
<td>Exceeding limits:</td>
<td><strong>Exceeding limits</strong></td>
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<tr>
<td>Experiencing ‘cost of activity’</td>
<td><strong>Exceeding limits</strong></td>
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<tr>
<td>Equating risk taking with satisfaction</td>
<td><strong>Exceeding limits</strong></td>
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<tr>
<td>Resisting ‘Fighting’ sleep;</td>
<td><strong>Exceeding limits</strong></td>
</tr>
<tr>
<td>Conflict between desire to sleep and activity</td>
<td><strong>Exceeding limits</strong></td>
</tr>
<tr>
<td>Seeking excitement on better days</td>
<td><strong>Exceeding limits</strong></td>
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<tr>
<td>Difficulty balancing rest and activity</td>
<td><strong>Exceeding limits</strong></td>
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<tr>
<td>Devaluing current activities</td>
<td><strong>Exceeding limits</strong></td>
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<tr>
<td>Undermining current ideas</td>
<td><strong>Exceeding limits</strong></td>
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<table>
<thead>
<tr>
<th>Managing Symptoms</th>
<th><strong>MANAGING SYMPTOMS</strong></th>
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<tr>
<td>Adapting pre-existing ideas</td>
<td><strong>Accommodating illness</strong></td>
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<tr>
<td>Developing new interests</td>
<td><strong>Accommodating illness</strong></td>
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<tr>
<td>Fitting new interests around illness symptoms</td>
<td><strong>Accommodating illness</strong></td>
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<tr>
<td>Finding alternative outlets for pre-illness roles</td>
<td><strong>Accommodating illness</strong></td>
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<tr>
<td>Prioritising activity</td>
<td><strong>Balancing activities</strong></td>
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<tr>
<td>Questioning validity of illness</td>
<td><strong>Balancing activities</strong></td>
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<tr>
<td>Increased recognition of consequences of activity</td>
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<td>Lowering standards</td>
<td><strong>Balancing activities</strong></td>
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<tr>
<td>Prioritising tasks</td>
<td><strong>Balancing activities</strong></td>
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<tr>
<td>Linking activity with relapse</td>
<td><strong>Balancing activities</strong></td>
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<tr>
<td>Managing illness through regular activity</td>
<td><strong>Balancing activities</strong></td>
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<table>
<thead>
<tr>
<th>Managing symptoms through eating; Becoming dependent upon food</th>
<th><strong>Managing symptoms through food</strong></th>
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<tbody>
<tr>
<td>Receiving pressure from others</td>
<td><strong>Being pressured</strong></td>
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<tr>
<td>Encouraged to work by others</td>
<td><strong>Being pressured</strong></td>
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<tr>
<td>Linking inability to work with increased pressures for others</td>
<td>Feeling guilty</td>
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<td>---------------------------------------------------------------</td>
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<tr>
<td>Interpreting others feelings as negative</td>
<td>Feeling disbelieved/not being believed</td>
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<tr>
<td>Believing others negative interpretations of self</td>
<td>Justifying illness experience</td>
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<tr>
<td>Loss of contact with others</td>
<td>Loss of contact with others</td>
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<tr>
<td>Disputing other's images of self</td>
<td>Justifying Illness</td>
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<tr>
<td>Recalling positive attributes of pre-illness self</td>
<td>Experiencing pre-illness personality as lost</td>
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<tr>
<td>Defining 'true' self by engagement in activities.</td>
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<tr>
<td>Expression of pre-illness values hindered by illness</td>
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<tr>
<td>Experiencing a loss of pre-illness attributes</td>
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<tr>
<td>Considering the impact of aging</td>
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<tr>
<td>Contrasting current and previous activities</td>
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<tr>
<td>Difficulties engaging in pre-illness activities</td>
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<tr>
<td>Feeling trapped</td>
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<td>Expressing frustration</td>
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<tr>
<td>Describing positive attributes of pre-illness self</td>
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<tr>
<td>Defining pre-illness self in terms of multiple activity based roles</td>
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<tr>
<td>Seeking to understand functioning from others</td>
<td>Difficulty defining self</td>
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<tr>
<td>Questioning contribution of illness to self-illness changes.</td>
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<tr>
<td>Seeking understanding through consulting others.</td>
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**IMPACT OF ILLNESS UPON THE SELF**

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<thead>
<tr>
<th>Describing positive attributes of post-illness self</th>
<th>Identifying positive self-illness change</th>
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<tbody>
<tr>
<td>Becoming more tolerant</td>
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<td>Becoming more forgiving</td>
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<td>Likening current and pre-illness self</td>
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<tr>
<td>Continuing to identifying with 'real' self</td>
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<td>Feeling un-changed</td>
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<tr>
<td>Seeking a return to pre-illness functioning</td>
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<tr>
<td>Identifying continuity in current/pre-illness plans</td>
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<tr>
<td>Continuing identification with pre-illness self</td>
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<tr>
<td>Continuing identification with pre-illness values</td>
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<tr>
<td>Difficulties contemplating longer time frames</td>
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<tr>
<td>Seeing plans as tasks</td>
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<td>Focus on practical tasks</td>
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<td>Abandoning plans for self</td>
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<td>Identifying ‘doing’ goals</td>
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<tr>
<td>Focussing on survival</td>
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<tr>
<td>Difficulty contemplating the future</td>
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<tr>
<td>Formulating plans for change in areas of new interest</td>
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<tr>
<td>Illness as part of the future</td>
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<tr>
<td>THINKING ABOUT THE FUTURE</td>
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<tr>
<td>Seeing poor health and desired job as incompatible;</td>
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<tr>
<td>Dismissing alternative employment</td>
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<tr>
<td>Goal attainment disrupted by rest</td>
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<tr>
<td>Conflict between necessities and personal goals</td>
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<tr>
<td>Seeing current goals as second</td>
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<tr>
<td>Developing plans in areas of new interest</td>
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<td>Seeing fulfilment as dependent upon recovery</td>
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<tr>
<td>Undermining current plans</td>
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<tr>
<td>Difficulties implementing plans</td>
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<tr>
<td>Conflict between future plans and current self</td>
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<tr>
<td>Linking goal fulfilment with improved health</td>
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<tr>
<td>Linking recovery and identification with pre-illness</td>
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<table>
<thead>
<tr>
<th>values</th>
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<td>Contrasting symptoms with requirements of pre-illness career.</td>
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Focussed Codes and Emerging Categories Identified Following Interview 2: Emily

<table>
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<tr>
<th>FOCUSED CODES</th>
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<th>EMERGING ABSTRACTED CATEGORIES</th>
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<tbody>
<tr>
<td>Disruption of activity</td>
<td>Uncertainty surrounding activity</td>
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<td>Experiencing a ‘cost for activity</td>
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<td>Considering the end of life</td>
<td>Uncertainty surrounding prognosis</td>
<td>BECOMING UNWELL</td>
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<td>Trying to establish a point of onset</td>
<td>Uncertainty regarding illness cause</td>
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<td>Experiencing anxiety</td>
<td>Experiencing multiple symptoms</td>
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<td>Experiencing stress</td>
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<td>Having up days and down days</td>
<td>Experiencing uncertain symptoms</td>
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<td>Experiencing uncertainty</td>
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<td>Experiencing improvement</td>
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<td>Separating effects of illness from self</td>
<td>Separating body and self</td>
<td>Experiencing changed Relationships</td>
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<td>Separating the mind and body</td>
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<td>Being controlled by the body</td>
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<td>Receiving a warning</td>
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<td>Blaming illness</td>
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<td>Separating body and self</td>
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<td>Fluctuating feelings of dependency</td>
<td>Becoming dependent</td>
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<td>Perceiving self as a burden</td>
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<td>Feeling guilty about distress</td>
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<td>[trying to be loveable]</td>
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<td>Feeling insecure</td>
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<td>Seeing survival as dependent on others</td>
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<td>Seeking reliability from others</td>
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<td>Keeping others close</td>
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<td>Avoiding conflict</td>
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<td>Feeling lonely</td>
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<tr>
<td>Keeping others close</td>
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<td>Being rejected by others</td>
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<td>Difficulty trusting others</td>
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<td>Keeping others close</td>
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<td>Loss of contact with others</td>
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<table>
<thead>
<tr>
<th>Seeing self as more afflicted than others</th>
<th>Justifying Illness</th>
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<tbody>
<tr>
<td>Being unaffected by others perceptions</td>
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<td>Linking choice and guilt</td>
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<td>Questioning validity of illness experience</td>
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<tr>
<td>Considering societal expectations surrounding the expression of distress</td>
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<td>Comparing self to others.</td>
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<table>
<thead>
<tr>
<th>Understanding symptoms biologically</th>
<th>Understanding illness biologically</th>
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<tbody>
<tr>
<td>Giving the body a voice; being warned by the body</td>
<td>UNDERSTANDING ILLNESS</td>
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<td>Identifying physiological correlates of illness</td>
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<td>Pathologising difficulties</td>
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<td>Linking symptoms to physiological correlates</td>
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<thead>
<tr>
<th>Receiving confirmation of illness</th>
<th>Questioning Illness</th>
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<table>
<thead>
<tr>
<th>Adjusting to illness</th>
<th>Accommodating illness</th>
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<tbody>
<tr>
<td>Accepting limitations</td>
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<td>Seeing post-illness lifestyle as normal</td>
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<td>Adjusting self expectations</td>
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<td>Experiencing a shift in values</td>
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<tr>
<td>Perceiving illness experience positively</td>
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<table>
<thead>
<tr>
<th>Questioning the effectiveness of controlling activity</th>
<th>Balancing activities</th>
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<table>
<thead>
<tr>
<th>Staying positive</th>
<th>Controlling illness</th>
</tr>
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<tr>
<td>Moderating exposure to distress triggers</td>
<td></td>
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<tr>
<td>Avoiding exposure to reminders of illness experience</td>
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<tr>
<td>[Avoiding distress]</td>
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<tr>
<td>Giving self permission to express negative feelings</td>
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<tr>
<td>Fluctuating feelings of dependency</td>
<td>Becoming dependent</td>
</tr>
<tr>
<td>Perceiving self as a burden</td>
<td></td>
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</table>

Contemplating the Future in CFS: A Grounded Theory Exploration of the Experience of Self and Contemplation of the Future Across Individuals with Chronic Fatigue Syndrome
<table>
<thead>
<tr>
<th>Feeling guilty about distress</th>
<th>Loss of contact with others</th>
</tr>
</thead>
<tbody>
<tr>
<td>Avoiding abandonment</td>
<td></td>
</tr>
<tr>
<td>[trying to be loveable]</td>
<td></td>
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<tr>
<td>Feeling insecure</td>
<td></td>
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<tr>
<td>Seeing survival as dependent on others</td>
<td></td>
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<tr>
<td>Seeking reliability from others</td>
<td></td>
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<tr>
<td>Keeping others close/Avoiding conflict</td>
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<tr>
<td>Feeling lonely</td>
<td></td>
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<tr>
<td>Keeping others close/Avoiding conflict</td>
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<tr>
<td>Being rejected by others</td>
<td></td>
</tr>
<tr>
<td>Difficulty trusting others</td>
<td></td>
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<tr>
<td>Feeling abandoned</td>
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<tr>
<td>Seeing self as more afflicted than others</td>
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<tr>
<td>Being unaffected by others perceptions</td>
<td></td>
</tr>
<tr>
<td>Linking choice and guilt</td>
<td></td>
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<tr>
<td>Questioning validity of illness experience</td>
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<tr>
<td>Considering societal expectations surrounding the expression of distress</td>
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<tr>
<td>Comparing self to others</td>
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<tr>
<td>Undermining achievements</td>
<td>Undermining achievements</td>
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<tr>
<td>Being seen as unreliable</td>
<td>Experiencing pre-illness personality as lost</td>
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<tr>
<td>Perceiving self as unreliable</td>
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<tr>
<td>Experiencing self change</td>
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<tr>
<td>Experiencing loss of self</td>
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<tr>
<td>Feeling incomplete (post-illness)</td>
<td></td>
</tr>
<tr>
<td>Difficulty confirming influences on self development</td>
<td>Difficulty defining self</td>
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<tr>
<td>Making sense of self change by comparing self to others.</td>
<td>IMPACT OF ILLNESS UPON THE SELF</td>
</tr>
<tr>
<td>Questioning the influence of ageing/time on illness-self changes</td>
<td></td>
</tr>
<tr>
<td>Identifying new positive aspects of the self</td>
<td>Identifying positive self-illness change</td>
</tr>
</tbody>
</table>

Contemplating the Future in CFS: A Grounded Theory Exploration of the Experience of Self and Contemplation of the Future Across Individuals with Chronic Fatigue Syndrome
<table>
<thead>
<tr>
<th>Becoming more sensitive to others</th>
<th>Retaining pre-illness goals</th>
</tr>
</thead>
<tbody>
<tr>
<td>Resisting self-illness changes</td>
<td>Identifying continuity in pre and post-illness goals</td>
</tr>
<tr>
<td>Becoming more empathic</td>
<td>Identifying continuity between pre and post illness self</td>
</tr>
<tr>
<td>Maximising quality of social contacts by becoming more attuned to others.</td>
<td>Intensification of pre-illness self following illness</td>
</tr>
<tr>
<td>Not taking things for granted</td>
<td>Perceiving pre-illness self as very active</td>
</tr>
</tbody>
</table>

| Continuing identification with pre-illness values |

<table>
<thead>
<tr>
<th>Experiencing frustration</th>
<th>Experiencing an inward battle</th>
</tr>
</thead>
<tbody>
<tr>
<td>Difficulty enacting self perception</td>
<td>Difficulty remaining hopeful [thinking about the future]</td>
</tr>
<tr>
<td></td>
<td>Identifying future fears</td>
</tr>
<tr>
<td></td>
<td>Experiencing a battle between hopes and fears</td>
</tr>
<tr>
<td></td>
<td>Feeling hopeless</td>
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</tbody>
</table>

| Difficulty contemplating the future |

<table>
<thead>
<tr>
<th>Accepting uncertainty</th>
<th>Seeing re-engagement as dependent upon recovery</th>
</tr>
</thead>
<tbody>
<tr>
<td>Integrating illness related learning into future existence</td>
<td>Seeing 'life' as on hold</td>
</tr>
<tr>
<td>Developing goals which integrate self-illness values</td>
<td>Feeling stuck</td>
</tr>
<tr>
<td>Enacting post-illness values through pre-illness interests</td>
<td>Waiting for recovery</td>
</tr>
<tr>
<td>Targeting pre-illness goals towards different ends</td>
<td>Predicting future relapses</td>
</tr>
<tr>
<td>Illness as part of the future</td>
<td>Experiencing a loss of pre-illness goals</td>
</tr>
</tbody>
</table>

| Contrasting current state with future goals |

**THINKING ABOUT THE FUTURE**

Contemplating the Future in CFS: A Grounded Theory Exploration of the Experience of Self and Contemplation of the Future Across Individuals with Chronic Fatigue Syndrome
<table>
<thead>
<tr>
<th>Questioning the possibility of independence</th>
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<tbody>
<tr>
<td>Seeking independence</td>
</tr>
<tr>
<td>Wanting to forget</td>
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</tbody>
</table>
### Focused Codes and Emerging Categories Identified Following Interview 3: Lucy

<table>
<thead>
<tr>
<th>FOCUSED CODES</th>
<th>RESEARCHER CATEGORIES</th>
<th>EMERGING ABSTRACTED CATEGORIES</th>
</tr>
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<tbody>
<tr>
<td>Experiencing multiple difficulties</td>
<td>Experiencing multiple symptoms</td>
<td>BECOMING UNWELL</td>
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<tr>
<td>Experiencing continual symptoms</td>
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<tr>
<td>Experiencing continual fear/anxiety</td>
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<tr>
<td>Experiencing fluctuating symptoms</td>
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<tr>
<td>Unchanging symptoms</td>
<td>Experiencing uncertain symptoms</td>
<td></td>
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<tr>
<td>Depending on others</td>
<td>Becoming dependent</td>
<td></td>
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<tr>
<td>Perceiving dependence as negative</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Experiencing a loss of independence</td>
<td></td>
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<tr>
<td>Feeling guilty</td>
<td></td>
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<tr>
<td>Receiving pressure from others</td>
<td>Being pressured</td>
<td>Experiencing changed Relationships</td>
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<tr>
<td>Refusing external financial supports</td>
<td></td>
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<tr>
<td>Being encouraged to seek 'treatment'</td>
<td></td>
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</tr>
<tr>
<td>Avoiding disclosure</td>
<td>Loss of contact with others</td>
<td></td>
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<tr>
<td>Feeling misunderstood</td>
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<tr>
<td>Feeling lonely</td>
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<tr>
<td>Questioning relationships</td>
<td></td>
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<tr>
<td>Feeling left out</td>
<td></td>
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<tr>
<td>Keeping others unaware</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Comparing self to others; feeling isolated</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Confidence reduced by others</td>
<td></td>
<td></td>
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<tr>
<td>Feeling stigmatised</td>
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<tr>
<td>Perceiving others' health to be a barrier to understanding</td>
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<td>Predicting disbelief</td>
<td>Justifying Illness</td>
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<tr>
<td>Feeling scrutinised by others</td>
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<td>Justifying validity of illness</td>
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<td>Feeling disbelief</td>
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<td>Feeling misunderstood</td>
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<tr>
<td>Seeking explanations 'excuses'</td>
<td>Questioning Illness</td>
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<tr>
<td>Managing activity through rest</td>
<td>Balancing activities</td>
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<tr>
<td>Awareness of personal limits</td>
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<tr>
<td>Managing emotional effects of illness through medication</td>
<td>Controlling illness</td>
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<td>Resisting post-illness changes</td>
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<tr>
<td>Distracting self from illness</td>
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<tr>
<td>Avoiding thoughts of failure</td>
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<tr>
<td>Difficulty discussing emotional issues</td>
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<tr>
<td>Illness leading to loss of confidence</td>
<td>Experiencing pre-illness personality as lost</td>
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<tr>
<td>Identifying positive illness self changes</td>
<td>Identifying positive self-illness change</td>
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<tr>
<td>Becoming more patient</td>
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<tr>
<td>Becoming more sensitive to others</td>
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<tr>
<td>Experiencing illness as a disruption to pre-illness self</td>
<td>Difficulty enacting self perception</td>
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<tr>
<td>Comparing current and pre-illness self</td>
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<tr>
<td>Describing positive attributes of the pre-illness self</td>
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<tr>
<td>Experiencing self as changed</td>
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<tr>
<td>Difficulty contemplating longer time-frames</td>
<td>Difficulty contemplating the future</td>
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<tr>
<td>Experiencing post-illness choices as limited</td>
<td></td>
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<tr>
<td>Difficulty contemplating alternative futures</td>
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<td>Difficulty visualising the future</td>
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<td>Avoiding contemplation of the future</td>
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<tr>
<td>Identifying future fears</td>
<td>Illness as part of the future</td>
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Contemplating the Future in CFS: A Grounded Theory Exploration of the Experience of Self and Contemplation of the Future Across Individuals with Chronic Fatigue Syndrome
<table>
<thead>
<tr>
<th>Loss of certainty about the future</th>
<th>Contrasting current state with future goals</th>
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<tr>
<td>Experiencing conflict between current and hoped for self</td>
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<td>Perceiving future as unobtainable</td>
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<td>Experiencing future goals as limited</td>
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<td>Linking employment and independence</td>
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<td>Anticipating difficulties returning to work</td>
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<td>Feeling stuck</td>
<td>Being Stuck</td>
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<tr>
<td>Unchanging symptoms</td>
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<tr>
<td>Experiencing no improvement</td>
<td></td>
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<tr>
<td>Perceiving life as stationary</td>
<td></td>
</tr>
<tr>
<td>Experiencing no improvement</td>
<td></td>
</tr>
<tr>
<td>Identifying continuity in future goals</td>
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<tr>
<td>Linking goals to internal urges</td>
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<td>Experiencing mental freedom</td>
<td>Re-capturing the past</td>
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<tr>
<td>Making plans</td>
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<tr>
<td>Not giving up</td>
<td></td>
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<tr>
<td>Making sense of 'giving up'</td>
<td></td>
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<tr>
<td>Perceiving 'good days' as false hope</td>
<td></td>
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<tr>
<td>Recalling experiences of 'giving up'</td>
<td></td>
</tr>
<tr>
<td>Increased desire to achieve pre-illness future goals</td>
<td></td>
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<tr>
<td>Resisting urge to 'give up'</td>
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<tr>
<td>Identifying continuity in pre and post-illness plans</td>
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<tr>
<td>Seeking a return to pre-illness functioning</td>
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<tr>
<td>Understanding future goals as longstanding</td>
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<tr>
<td>(Others) seeking return of pre-illness self</td>
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<tr>
<td>Difficulty remaining hopeful</td>
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<tr>
<td>Not accepting illness</td>
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</table>
APPENDIX 16

(Examples of Early Stage Memos)
**MEMO: Justifying the Illness Experience by Comparing Self to Others**

There is a sense that people construct CFS as unreal or false and thus unjustified. I wonder if this may relate to media and societal attitudes towards CFS. I need to see if this arises without prompting.

Thus by looking towards the emotional experiences of others, individuals seek to ascertain whether their own experiences can be justified as 'real' and thus acceptable? Need further confirmation/disconfirmation of this in other interviews.

**MEMO: Linking Recovery to Identification with Pre-Illness Values**

Again this category of experience was prominent for Lucy and Margaret who clearly seem to define their pre-illness selves in terms of 'doing roles'. These women saw themselves as career minded and self-sufficient and in turn describe a strong urge to regain this aspect of the self. Thus for both of them there is a desire to return to work (which Lucy explicitly links to the desire to re-capture independence).

The focus on recovery in order to re-capture aspects of the pre-illness self seemed to be linked to the notion that attributes of the pre-illness role are not accessible for Lucy and Margaret in their current states of being. This again seemed to relate to a focus on 'doing' and activity although when Margaret does shift to a more value laden appraisal goals are identified (see integration code). Consequently re-engagement with these roles is seen as dependent upon physical health and thus recovery. This seems to be associated with a tendency to predict possible failure and anticipate difficulties engaging in this role by virtue of illness. I wonder if this may link in to the need to avoid thoughts of the future as this must be very difficult. Indeed Emily describes a great sense of loss when contemplating the now inaccessible ‘active’ parts of the pre-illness self.

Need to explore links between seeing goal achievement as dependent upon recovery, ensuing feelings and impact upon the future).

Links: Avoiding contemplation of the future, comparing pre and current selves, Acceptance.

**MEMO: Protecting Self by Resisting Self-Illness Changes**

This code reflects the tendency to perceive self-illness changes as negative, resulting in a need to resist and minimise their effect.
I wonder if this relates to the tendency to identify with pre-illness self as the 'true' self. What would it mean to accept the current self as real? Perhaps it would imply that the negative changes are somehow wanted, feeding into the sense of being disbelieved by others. I need to explore further the meaning of acceptance/resistance if arising in future interviews.

**MEMO: Questioning the Validity of Illness Experience**

Some individuals describe a continuing tendency to question the validity of their experiences. One possible consequence identified (need to explore this more) is to wonder whether the illness is psychological and whether they should actually be able to overcome their difficulties. I wonder what conditions questioning validity of experiences comes under? It seems to link closely with the tendency to feel scrutinized and disbelieved by others, it may also link to societal attitudes towards CFS (although little evidence of this as yet, need to confirm/disconfirm).

A further consequence of this process seems to be the need to justify the fact that the illness has not been self-imposed when interacting with others. This seems to be associated with feelings of guilt and experiences of 'not being believed'.

This may also link with the code regarding the need to justify validity of emotional expression when being with others.

**MEMO: Developing Goals Which Integrate Pre-and Post-Illness Values**

Where individuals were able to acknowledge the possibility of ongoing illness there was some evidence of an integration of pre and post-illness self-concepts (consistent with Charmaz; Fennell and Clarke and James).

Emily's focus on integrating pre and post-illness values was in some ways reminiscent of the 'radicalised' self described by Clarke & James (2003) in that her pre-illness values have been intensified by the illness experience and she is now considering ways of drawing upon these experiences to help other people. This is something Emily feels she can work towards (though distance learning courses) despite ongoing illness. In this regard she describes most of the illness experience as positive and wanted. It is however important to acknowledge that later in the interview she does state a desire to return to normal and be a full time student, as if the pre-illness goals are still there to some extent.

For Margaret too, despite describing a focus on returning to the pre-illness self there is some evidence of attempts to integrate pre and post illness values. This can be seen in
terms of Margaret's perception of herself as a teacher (adapting this to teach English to friends). However, Margaret also describes adapting new interests developed through the illness experience towards achieving pre-illness goals (of facilitating organisational/systemic change). Again, however, Margaret in other parts of the interview described that she had no achievable goals for herself or goals that fitted with illness.

I wonder what acknowledging these integrated goals means for individuals. Both Emily and Margaret show a kind of fluctuation between seeking a return to pre-illness self and at other times accepting an integration of pre and post-illness values. Does this link uncertainty within CFS and the inward battle and need to keep hope alive? What would it mean to accept integration of pre and post illness values? Is this seen as synonymous with losing hope/giving up?

Need to explore more what it is link to hold integrated goals for self and others, what does the future feel like with this different goals.
RESEARCH LOGBOOK

A logbook of the research experience accumulated over the three years of the training programme
## Research Log Checklist

<table>
<thead>
<tr>
<th></th>
<th>Formulating and testing hypotheses and research questions</th>
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</thead>
<tbody>
<tr>
<td>2</td>
<td>Carrying out a structured literature search using information technology and literature search tools</td>
<td></td>
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<tr>
<td>3</td>
<td>Critically reviewing relevant literature and evaluating research methods</td>
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</tr>
<tr>
<td>4</td>
<td>Formulating specific research questions</td>
<td></td>
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<tr>
<td>5</td>
<td>Writing brief research proposals</td>
<td></td>
</tr>
<tr>
<td>6</td>
<td>Writing detailed research proposals/protocols</td>
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<tr>
<td>7</td>
<td>Considering issues related to ethical practice in research, including issues of diversity, and structuring plans accordingly</td>
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<tr>
<td>8</td>
<td>Obtaining approval from a research ethics committee</td>
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<tr>
<td>9</td>
<td>Obtaining appropriate supervision for research</td>
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<tr>
<td>10</td>
<td>Obtaining appropriate collaboration for research</td>
<td></td>
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<tr>
<td>11</td>
<td>Collecting data from research participants</td>
<td></td>
</tr>
<tr>
<td>12</td>
<td>Choosing appropriate design for research questions</td>
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<tr>
<td>13</td>
<td>Writing patient information and consent forms</td>
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<tr>
<td>14</td>
<td>Devising and administering questionnaires</td>
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<tr>
<td>15</td>
<td>Negotiating access to study participants in applied NHS settings</td>
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<tr>
<td>16</td>
<td>Setting up a data file</td>
<td></td>
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<tr>
<td>17</td>
<td>Conducting statistical data analysis using SPSS</td>
<td></td>
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<tr>
<td>18</td>
<td>Choosing appropriate statistical analyses</td>
<td></td>
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<tr>
<td>19</td>
<td>Preparing quantitative data for analysis</td>
<td></td>
</tr>
<tr>
<td>20</td>
<td>Choosing appropriate quantitative data analysis</td>
<td></td>
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<tr>
<td>21</td>
<td>Summarising results in figures and tables</td>
<td></td>
</tr>
<tr>
<td>22</td>
<td>Conducting semi-structured interviews</td>
<td></td>
</tr>
<tr>
<td>23</td>
<td>Transcribing and analysing interview data using qualitative methods</td>
<td></td>
</tr>
<tr>
<td>24</td>
<td>Choosing appropriate qualitative analyses</td>
<td></td>
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<tr>
<td>25</td>
<td>Interpreting results from quantitative and qualitative data analysis</td>
<td></td>
</tr>
<tr>
<td>26</td>
<td>Presenting research findings in a variety of contexts</td>
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</tr>
<tr>
<td>27</td>
<td>Producing a written report on a research project</td>
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<tr>
<td>28</td>
<td>Defending own research decisions and analyses</td>
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</tr>
<tr>
<td></td>
<td>Activity</td>
<td>Status</td>
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<tr>
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<td>Submitting research reports for publication in peer-reviewed journals or</td>
<td>Ongoing</td>
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<td>edited book</td>
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<td>30</td>
<td>Applying research findings to clinical practice</td>
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</table>
CLINICAL DOSSIER

This section of the portfolio contains a brief overview of the experience obtained across the five clinical placements alongside summaries of the five formal case reports conducted across the three years of training.

Placement documentation and full versions of the case reports are presented in Volume 2.

All names and other identifiable information have been removed to ensure client anonymity.
SUMMARY OF CLINICAL EXPERIENCE

To follow is a summary of clinical experiences gained across the five training placements. Full placement details can be found in Volume 2.
SUMMARY OF PLACEMENT EXPERIENCE

**Adult Placement Details**

**Dates:** September 2004 - March 2005  **Base:** Split placement across an adult Community Mental Health Team and a Specialist Health Psychology service\(^{35}\).

**Summary of Experience**

My work within the CMHT involved undertaking (clinical, cognitive and neuropsychological) assessments and individual therapeutic work (largely within a cognitive behavioural framework) with individuals presenting with a range of difficulties including: anxiety; depression; non-epileptic seizures; longstanding interpersonal difficulties and head injury, these difficulties often occurring in tandem with one another. Within the specialist health psychology service individual work focussed largely on issues of adjustment to physical health difficulties including: difficulties in executive function following a head injury; chronic eczema; chronic pain; scoliosis and body image difficulties. I also co-facilitated a psycho-educational/self-management group-based intervention for individuals with Chronic Fatigue Syndrome and supported my supervisor in undertaking a staff training (for diabetes specialist nurses) day on cognitive behavioural approaches to diabetes. Research skills were developed through undertaking a Service Related Research Project exploring levels of supervision and CPD among local psychologists. I also researched and produced a patient leaflet regarding a computer-based self-management programme for depression.

**People with Learning Disabilities Placement**

**Dates:** October 2005- March 2006.  **Base:** Community Mental Health Team for Older People, Farnham Road Hospital.

**Summary of Placement Experience**

This placement comprised a mix of individual work within outpatient and residential settings. This work was largely focussed around anxiety management, low mood and fear of falling and was undertaken predominantly within a cognitive behavioural framework. In addition, behavioural assessment, formulation and indirect intervention skills were strengthened through undertaking detailed assessments of individuals within residential settings in conjunction with a specialist Behaviour Service attached to the team. This work also comprised liaising with other MDT members in undertaking/feeding back assessment results.

\(^{35}\) Details of placement location are not given in order to preserve the anonymity of clients/teams referred to within case report summaries.
Presentation/training skills were strengthened by undertaking a day long training workshop within a local residential home focussed around supporting a client with dementia. Group work-skills were built through co-planning and facilitating a mindfulness meditation group. Cognitive assessment skills were strengthened through use of a range of developmental/neuropsychological assessment measures. The placement also offered a range of opportunities for adapting pre-existing clinical skills for individuals of varying cognitive abilities.

**Children and Young People Placement Details**

**Dates:** April 2006- September 2006. **Base:** Child and Adolescent Mental Health Service.

**Summary of Experience**

My work within this Tier 3 placement setting included contact children (of different ages) and their families and included contributing to assessments of various cognitive, developmental and social communication issues (including an assessment under the remit of 'Child Health'). Individual work, focussed around anxiety and behavioural management, was undertaken largely within Behavioural and Cognitive Behavioural Frameworks, although also drawing upon developmental, systemic and narrative ways of thinking. Group work skills were strengthened through co-implementing a social skills group for boys with Asperger's syndrome. Observations of local Tier 2 services were undertaken alongside a joint home visit assessment and indirect brief intervention within this service. As part of my assessment and individual work, liaison was undertaken with teaching staff at local schools. I also met with a local Educational Psychologist to discuss service provision issues. Multi-disciplinary work was undertaken within the team through observations, joint assessments and attendance at team meetings. Additional psychometric training was also undertaken from the local Head of Psychological services. Presentation skills were strengthened through presenting, chairing and facilitating a journal club meeting and undertaking a Narrative Therapy presentation with a colleague.

**Older Placement Details**

**Dates:** October 2006- March 2007. **Base:** Community Mental Health Team for Older People.

**Summary of Experience**

This placement was situated in a community mental health team for older people attached to a hospital site, which included inpatient wards specialising in caring for older adults with dementia and mental health difficulties, alongside a day hospital. I consequently conducted
various interventions/assessments across in-patient, out-patient and community settings (client homes) the nature of which included: cognitive assessment of individuals with memory difficulties (as part of multi-disciplinary assessments exploring the possibility of cognitive decline); inpatient assessments considering the suitability for further therapeutic input and outpatient work undertaken within a cognitive behavioural framework, typically focussed around issues of adjustment related to changing life circumstances associated with older adulthood. Knowledge and familiarity with psychodynamic models of thinking were furthered through reflecting upon alternative formulations in working with a client who had experienced longstanding emotional distress. As part of my individual therapeutic work I was required to liaise with ward staff on several occasions, thus gaining an insight into the complexities of inpatient work within a multi-disciplinary setting.

**Specialist Placement**

**Dates:** April 2007 - September 2007.

**Base:** Paediatric Psychology Service.

This placement was undertaken within a Paediatric Psychology department of a large urban hospital. The Psychology service covered inpatient (generic and specialist children’s wards) and outpatient work with children aged 0-18 addressing a range of issues including: issues of adjusting to/managing emotions associated medical diagnoses; preparatory work prior to undergoing surgical procedures; management of physical conditions occurring in the absence of a clear organic cause e.g. stomach aches, chronic fatigue, chronic pain; cognitive, neuropsychological and developmental assessments; assessment of feeding difficulties/weight related issues; exploration and management of behavioural problems occurring in the context of a medical diagnosis. Interventions comprised preparatory work and anxiety management/parenting work across inpatient and outpatient contexts, alongside liaison/consultation with senior medical and nursing staff. Specifically, I undertook some intensive work with a child undergoing major reconstructive plastic surgery. Other therapeutic work tended to be brief and undertaken within a cognitive behavioural framework. However, I was able to further my narrative, systemic and psychodynamic thinking skills in developing client formulations¹, whilst also broadening my awareness of service provision issues in the context of Paediatric Diabetes. I also attended and contributed within regular multi-disciplinary psycho-social ward rounds on the general children’s ward.
SUMMARY OF CASE REPORTS

This Section of the portfolio contains summaries of the five case reports conducted across the clinical placements.
Adult Mental Health Case Report Summary: 1

Cognitive Behavioural Therapy with a 36-Year-Old-Woman Presenting with Social Phobia

Reason for Referral
Jessica, a 36-year-old woman, was referred to the Community Mental Health Team’s (CMHT) Psychology service, by her Community Psychiatric Nurse (CPN) who requested support with Jessica’s difficulties interacting socially and leaving home alone.

Presenting Difficulties
Jessica described experiencing longstanding anxiety when contemplating leaving home without her partner, or if briefly separated from him whilst out, which had worsened since becoming pregnant with her now 10 month old son. She feared others would be critical of her, often experiencing mental images of herself looking anxious and “stupid”. Subsequently, Jessica avoided all social situations, only leaving home with her partner and 10 month old son, who made her feel less noticeable and distracted her attention from feelings of anxiety. Jessica sought a practical treatment approach, aiming to increase her independence and reduce her anxiety.

Assessment
I assessed Jessica via semi-structured clinical interviews across two sessions, during which information on her current difficulties and background history was collected including information about her history of eating disorder and alcohol dependency (both of which ceased during pregnancy). In addition, psychometric assessment tools suggested that Jessica was experiencing moderate-severe levels of depression and moderate levels of anxiety (assessed using the Beck Depression and Anxiety Inventories, Beck (1961) and (1988) respectively). The Social Cognitions Questionnaire (SCQ, Wells, Stopa & Clark 1993) was administered as means of attaining qualitative information on Jessica’s difficulties mixing socially and highlighted frequent, strongly believed (80%-100%), thoughts of vulnerability and fears of looking foolish/being rejected. A detailed risk assessment suggested that Jessica’s BDI responses were not associated with suicidal ideation or indicative of post-natal depression. Jessica’s negative thoughts and low mood also appeared to be a product of her concerns of social evaluation rather than a cause.
Formulation
Jessica’s difficulties appeared typical of individuals suffering from social phobia and were subsequently conceptualised using Clarke and Wells cognitive model of anxiety (1995). Here, Jessica’s experiences of rejection as a child were hypothesised as resulting in core beliefs about herself as inadequate/defective and conditional assumptions pertaining to the likelihood of rejection from others. Attention was paid to the development of various coping strategies as a means of mediating distress associated with such beliefs. Specifically, Jessica’s previous alcohol dependency was conceptualised as a means of mediating anxiety, thus allowing her to have some independence. Similarly, her restrictive/bulimic eating patterns were conceptualised as a means of blocking negative affect. Consequently, Jessica’s recent abstinence and motivation to engage in healthy eating patterns during pregnancy led to increasing anxiety and thus avoidance, eliciting further self-critical thoughts and a lowering of mood. Maintaining factors consistent with Clarke and Wells model of social phobia were also considered (e.g. self-monitoring) alongside Jessica’s wider socio-economic and relationship circumstances.

Intervention
The initial intervention comprised 5 sessions of individual therapeutic work undertaken within a cognitive behavioural framework. Here Jessica was encouraged to learn about the physiological effects of anxiety and their relationship to threat-related thoughts. Imaginal exposure and distress tolerance techniques were also explored as a means of preparing Jessica for subsequent behavioural experiments designed to test out her thoughts about being rejected/laughed at by others in social situations. However, after five sessions Jessica experienced relocation to a more over-looked property. She also experienced difficulties in her relationship with her partner, which left her fearing that he may leave her. Jessica subsequently felt overwhelmed by her social anxieties and increasingly unable to leave home alone, resulting in a worsening of her mood.

Reformulation
In light of these difficulties, Jessica’s problems were re-formulated to give extra emphasis to her low mood. However, rather than utilising a model of depression these experiences were conceptualised using Fennell’s cognitive model of self esteem. Here Jessica’s longstanding negative judgements about herself were conceptualised as resulting in standards or rules for living pertaining to her inability to cope alone (both generally and in response to emotions associated with criticism/rejection). These subsequently necessitated a reliance concealment/avoidance to evade rejection and reliance on others to ensure she would be able
to cope if such experiences did occur. Subsequently, her relocation to an overlooked property led Jessica to believe she would be unable to abide by her rules (avoid rejection, remain inconspicuous), even at home (previously a safe haven). Furthermore, relationship difficulties led her to believe she would be left alone and thus unable to cope with any anticipated rejection. As such, consistent with Fennell (1997), the remainder of my sessions with Jessica utilised cognitive restructuring techniques in addressing her negative thoughts whilst also encouraging Jessica to monitor her mood with a view to increasing engagement with activities associated with pleasure and mastery (consistent with Beck, 1976).

Outcome
During this work, Jessica was able to both leave home alone without her partner on several occasions and engage in brief conversations with strangers in the shops. Unfortunately, before the work could be continued (and thus formally evaluated) Jessica experienced a serious physical health problem requiring hospitalisation, subsequently rendering her unable to undertake further input.

Critique
In considering the above intervention I reflected upon the complexity of Jessica’s initial presentation and the associated dilemmas posed with regards to whether to intervene at the level of her low mood or her underlying difficulties interacting socially. Here I considered whether my initial focus on Jessica’s social anxieties was possibly influenced by both my awareness of the client-therapist differences between Jessica and myself and, due to my early stage in training, my desire to produce a “good” intervention. I also reflected upon professional issues raised by the case, specifically the importance of clear delineation of professional roles within the CMHT due to the various social, medical and psychiatric issues involved alongside my positive experiences of working closely with her CPN in managing/assessing risk. Given the impact of Jessica’s deteriorating health in ending our intervention prematurely, I concluded by recommending that further work should continue to address Jessica’s underlying ‘bottom line’ beliefs and associated negative thinking patterns.
Adult Mental Health Case Report Summary: 2

AMH Case Report 2: Development of a Self-Management Group for Individuals with Chronic Fatigue Syndrome

Reason for Referral
Set within a secondary care Specialist Psychology service, this case report describes the development of a short-term, group-based intervention for five individuals who had been referred for support in managing their Chronic Fatigue Syndrome (CFS). This was the fourth in a series of psycho-educational groups for individuals with chronic conditions and aimed to facilitate acceptance and active self-management of CFS, through integrating standard CBT approaches with ‘third wave’ acceptance-based theories.

Assessment
The five individuals (four women and one man) were assessed individually to screen their suitability for the group which was to be co-facilitated by a colleague and myself. Suitability was determined by facilitating individual decision making about whether the group was appropriate, in the context of available alternatives. Here, the group’s individualised and acceptance-based nature was made explicit. All five individuals assessed were offered and subsequently accepted a place within the group. To provide a baseline with which to evaluate the effectiveness of the group, a number of psychometric measures were administered including: The Fatigue Severity Scale (FSS, Krupp, La Rocca, Muir-Nash & Steinberg, 1989) and The Fennell Phase Inventory (FPI, Fennell, 1993, Jason et al, 2000a/2000b), which is designed to assess progression through various stages of CFS from initial crises through stabilisation, integration and resolution.

Formulation
The over-arching conceptualisation adopted was consistent with Chalder’s (1995) cognitive behavioural theory, which highlights various biological, psycho-social and psychological factors in developing/maintaining CFS. The work of Surawy, Hackman, Hawton and Sharpe (1994) was also considered with regards to the hypothesised underlying role ‘perfectionistic’ standards pertaining to achievement, which became compromised following illness and thus serve to maintain fatigue, through perpetuating desires to engage in high levels of activity incompatible with the de-conditioned physical state. In addition, the impact of chronic illness on identity was also considered as a possible factor maintaining distress.
**Intervention**

The group aimed to facilitate acceptance of and adjustment to CFS and took place over 8-weeks. A major aim was to individualise the treatment by encourage group members to identify and work on meaningful and personal goals across the course of the group. Here a predominantly CBT focus was retained by including sessions on: relaxation; activity pacing; exploration of negative thinking patterns and relapse prevention. However, in light of the evidence base, this format was also integrated alongside “third-wave” approaches to chronic illness emphasising the relationship between negative thinking patterns and action/inaction alongside active self-management through using mindfulness mediation techniques to aid symptom acceptance and facilitating engagement with meaningful goals. In addition, as individuals with chronic illness experience difficulties communicating their needs to healthcare professionals/family we also included a session addressing communication/assertiveness skills, using the pre-established techniques. During the intervention one individual discontinued attending the group due to a relapse of her CFS. Issues of group process and group dynamics were considered and reflected upon throughout.

**Outcome**

Consistent with the above aims as the group progressed, there was a shift away from discussions of symptoms/functional impairment toward the contemplation of meaningful existences embracing CFS. Although pre and post group assessment measures were not fully completed for all members of the group, analysis of the results suggested that all individuals remained severely fatigued, which was perhaps unsurprising, given the group’s acceptance-based focus. With regards to the FPI, one group member had shifted from the stabilisation phase through to the resolution phase. Another individual who was already identifying with the resolution phase remained in this category, although her scores on the Crisis and Stabilisation indexes had fallen and increased respectively suggesting improvement. The final group member did not want to complete the post-group measures fearing that these may be called upon by her insurers. Analysis of qualitative feedback forms assessing client satisfaction revealed that most aspects of the group including, individual sessions were rated as good to very good.

**Critique**

In considering the above intervention I reflected upon the challenges posed by the complexities attached to attempts to integrate important elements of individual (unique treatment plans/formulations) and psycho-educational group (standardised techniques/formats) interventions within a single group-based forum. I also considered the
non-expert approach of myself and my co-facilitator whereby we facilitated discussion surrounding the available resources, with the final decision as to which techniques were utilised residing with the individual (consistent with Expert Patient Movements); this flexibility and non-didactic approach appearing to be important in contributing to the outcomes observed. In considering the limitations of my work I reflected upon the limited amount of completed pre-and post-group data and difficulty attributing the outcomes observed directly to the group intervention. I also considered factors associated with varying degrees of engagement with the group process.
People with Learning Disabilities Case Report Summary

An Extended Assessment of ‘Challenging’ Behaviours Exhibited by a Young Man with a Rare Congenital Syndrome

Referral Process
This report presents an extended assessment of Tom, a 26 year old male living in residential care. Tom has a rare congenital syndrome associated with significant visual and hearing impairments, airway blockages and delayed cognitive/physical development.

Tom was described by his support staff as having profound and multiple learning disabilities and was referred to the Behavioural Service (BS), within the Community Team for People with Learning Disabilities (CTPLD) by his residential staff. At the time of referral Tom was engaging in multiple ‘aggressive’ and ‘self-injurious’ behaviours. Specifically he would often throw himself to the floor when distressed. He would also smear faeces over himself/furniture and would sometimes cram large amounts of food into his mouth at mealtimes. The BS team subsequently requested that I undertake an extended assessment of Tom’s behavioural difficulties, to generate recommendations for their management.

Initial Assessment
I initially met with Tom’s key worker to undertake a Functional Assessment Interview consistent with British Psychological Society recommendations. Here, information was gained about Tom’s behaviours of concern alongside his likes, dislikes and ability to communicate his needs in other ways. A risk assessment was also undertaken to assess the level of associated risk for Tom, other residents and staff. Issues related to gaining consent were discussed.

Initial Hypotheses
Initial hypotheses were generated surrounding possible functions of Tom’s behaviours. Specifically, information from the FAI suggested that his aggressive behaviours allowed him to escape demands, whilst the self-injurious behaviours and faecal smearing provided him with stimulation during periods of inactivity. The function of the ‘food cramming’ was also hypothesised as fulfilling a physiological/sensory need whilst also allowing Tom to escape

36 This aspect of the title has been changed to remove reference to the specific condition, which due to it’s rarity could compromise the client’s anonymity.

Summary of Case Reports
demands associated with the mealtime routine, by ensuring that he is removed from the table by staff.

**Extended Assessment**

In order to explore these hypotheses further, a detailed behavioural assessment was undertaken. Specifically, informal observations of Tom’s environment and routines associated were undertaken using the ‘ecological analysis’ framework proposed by O’Neill et al (1997). I also met with Tom’s mother to ascertain whether his behaviours persisted at home. The Motivational Assessment Scale (MAS, Durand & Crimmins, 1998) was utilised to explore functions underlying Tom’s behaviours, whilst his developmental level was assessed using The Vineland Adaptive Behavior Scales (VABS, Sparrow, Balla & Cichetti, 1984). The frequency of Tom’s behaviours and environmental contexts contributing to their occurrence was assessed through staff completion of ABC (antecedents, behaviours, consequences) charts. Momentary Time Sampling was also undertaken to explore further patterns in their occurrence. Formal speech and language therapy and occupational therapy were requested and a literature review of Tom’s congenital syndrome was undertaken. Diversity issues were reflected upon throughout the assessment process.

The results of the assessment suggested that activities were frequently ‘sprung’ on Tom with little warning, typically consisting of relatively complex commands, or attempts to remove favoured toys, or food that Tom was ‘cramming’. As a consequence Tom would react with aggressive/self-injurious behaviours, resulting in his being left alone to calm down (during which time he would throw himself against the floor, breathing heavily) or having the toy returned to him; faecal smearing occurred during periods of inactivity. These findings were confirmed across the Ecological Analysis, MTS/ABC chart analyses and interviews with Tom’s mother. Consistent with this, the MAS highlighted a strong sensory need underlying his smearing and biting behaviours whilst aggressive and self-injurious behaviours were driven by escaping demands and gaining tangibles (access to preferred toys). On the Vineland Tom attained a developmental level of between 0-2 years, with specific difficulties in expressive communication and play skills. The literature review highlighted evidence of sensory issues pertaining to a need to adopt rigid postures (e.g. lying on the floor) and use excess force when making contact with others as a means of assisting spatial awareness.

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37 But not completed before the end of my placement
Formulation
The results of the extended assessment led to my conceptualising Tom’s difficulties within the integrative-behavioural framework, emphasising genetic, developmental and contextual influences on their occurrence. Here, Tom’s congenital syndrome and associated adaptive functioning and communication difficulties were thought to be limiting his use of developmentally ‘appropriate’ methods of communication his needs. Furthermore, Tom’s sensory difficulties also shaped his experience and understanding of the world, influencing his behaviour and rendering him reliant on food and self-injurious behaviours as a means of gaining spatial awareness. Relevant triggers in terms of demands, sensory needs and interactions with staff were considered within the formulation, as were biological (sensory gain associated with behaviours), behavioural (ability to gain tangibles/escape demands) and environmental maintaining factors (staff attitudes concerning the importance of normalisation, exacerbating attempts to set inappropriate demands).

Outcome and Recommendations
Consistent with a ‘goodness of fit’ approach to intervention, a Positive Behavioural Support model was utilised in developing recommendations relevant to Tom’s residential context, through a mix of proactive and reactive strategies targeting the precipitants and maintaining consequences associated with his behaviours. These recommendations were fed back to the staff team alongside members of the Behaviour Service, who would subsequently provide the staff team with support in their implementation. It was agreed that the effectiveness of the recommendations would be monitored within a Periodic Service Review.

Critique
Within the critique I reflected upon importance of adopting a context-based framework when assessing people with learning disabilities, whilst also highlighting difficulties attached to undertaking more holistic assessments in parallel with other professionals. I also considered the importance of patterning within relationships between staff teams and other professional groups, reflecting upon the ways in which longstanding interactions between Tom’s care staff and the Behavioural Service may have influenced the assessment process. These reflections were then used to identify learning points for myself within future work, specifically with regards to the importance of explicating residential staff feelings about input, in order to facilitate their engagement within the therapeutic process.
An Extended and Cognitive Assessment of a 10 year Old Girl Presenting with Fears and Behavioural Difficulties

Reason for referral
The referral information for ten year old Samantha Hastings consisted of a brief letter from the General Practitioner, requesting Child and Adolescent Mental Health Service (CAMHS) input with regards to her various “emotional problems”.

Presenting Difficulties
Samantha presented with several longstanding fears including, aeroplanes and insects. More recently, she had become fearful of thunderstorms and eating in the school canteen. If exposed to feared situations, Samantha would cry, or state that she had a tummy ache and withdraw. Samantha found it hard to explain her fears but described being scared of a flickering light in the canteen, the presence of which had been corroborated by her teachers. Samantha also displayed some behavioural issues, seeming to have difficulty understanding the impact of her behaviour on others. She was also prone to making “inappropriate” comments, sometimes telling teachers that she ‘loved them’.

Initial Assessment
I initially undertook a clinical interview with Samantha, her mother and sisters, within which evidence of: speech and language delay; learning difficulties (and history of Learning Disability within the family); sensitivity to sound and co-ordination difficulties were highlighted. Here, Samantha’s difficulties were identified as longstanding and seemingly associated with difficulties understanding ‘appropriate’ ways of behaving and a limited awareness of other peoples’ emotions. Mrs Hastings also alluded to some difficult familial events which she requested that we discuss at a later date. A risk assessment revealed no evidence of abuse/neglect.

Initial Hypotheses
Following the assessment, a number of possibilities were considered. Primarily, as Samantha’s fears and behaviour appeared more consistent with that of a younger child, I considered whether she may have a more global intellectual disability. I was also struck by her idiosyncratic language and difficulties understanding the perspectives of other people, subsequently considering the possibility of additional social communication difficulties or a
specific developmental disorder such as Autistic Spectrum Disorder (ASD). Similarly, I was curious as to whether her fidgety/excitable presentation reflected additional attention/concentration difficulties or ADHD. I subsequently planned to undertake an extended assessment exploring the possibilities of Learning Disability, ASD and ADHD.

Extended Assessment
An extended assessment was undertaken across a period of 6 sessions drawing upon a number of sources including: review of previous SALT and OT assessments; a cognitive assessment of Samantha’s level of intellectual functioning; Psychometric assessment of Samantha’s anxiety and attention/concentration difficulties. Detailed interviews with staff at Samantha’s school were also undertaken in order to consider their understanding of Samantha’s intellectual level and explore evidence of possible social communication difficulties. I also met with Samantha’s mother to consider the extent to which various familial events alluded to within the initial assessment may have exacerbated Samantha’s presenting difficulties.

The results of the above information suggested that Samantha was currently experiencing high levels of anxiety. However, although recent family events (parental divorce/bereavement) may have exacerbated this anxiety there was evidence that her behaviours had pre-dated these events. The cognitive assessment suggested that Samantha was performing approximately 1-2 years below current school estimates. However, whilst Samantha’s globally lowered cognitive profile was not typically consistent with ASD interviews suggested that there was evidence of a range of criteria associated with ASD e.g. stereotyped behaviours/impairment in imaginative play. Although Samantha’s performance on the WISC highlighted some evidence that she benefits from structure (consistent with children with attention/concentration difficulties), it was felt that her elevated scores on a Psychometric assessment of hyperactivity may have been influenced by Samantha’s lowered level of cognitive functioning.

Formulation
The results of the extended assessment were conceptualised using an integrative formulation which emphasised the way Samantha’s intellectual disability may render her vulnerable to interpreting her environment as threatening and thus experiencing anxiety, which she tends to communicate somatically. Similarly, her distractibility, active behaviour and apparent social communication difficulties were conceptualised as the product of her combined difficulties understanding her environment and apparent auditory sensitivities. With regards to precipitating factors, these vulnerabilities were hypothesised as making Samantha vulnerable to experiencing anxiety in response to recent changes in the family environment, thus
resulting in an escalation of her fears/phobias. In understanding the maintenance of Samantha’s behaviour, it was hypothesised that Samantha may be experiencing additional strain due to her educational staff’s limited awareness of the extent of her intellectual difficulties. Wider systemic factors: lack of school support; high levels of family stress and family perceptions surrounding Samantha’s behaviour and associated failure to implement clear boundaries, were also considered as possible maintaining factors.

**Outcome**

The results of the assessment were fed back within a meeting with Samantha’s Educational Psychologist and Special Educational Need Co-ordinator. However, it was acknowledged that Samantha may benefit from a more formal assessment of her developmental level in order to confirm the extent to which her attention/concentration and social communication difficulties were commensurate with her intellectual level. Whilst it was agreed that further assessment, would take priority over therapeutic work, it was recommended that Samantha’s parents should be helped to develop their understandings of her difficulties in order to facilitate their use of behavioural management strategies. Possible methods of facilitating Samantha’s understanding of socially ‘appropriate’ behaviours were also discussed alongside potential cognitive behavioural/behavioural interventions for addressing her anxieties and phobias.

**Critique**

In reflecting upon the intervention, I considered the way in which the power differential between Samantha and myself may have influenced the assessment process. I also reflected upon my initial reluctance to consider ‘diagnostic’ terms, noting how this had shifted as I began to recognise the benefit of such labels in signposting the family towards further avenues of support. Finally, I considered my decision not to involving Samantha’s father more within the assessment process considering this in light of my experiences growing up within a family where my father was largely absent. Here, I looked back upon the largely ‘practical’ focus of my supervision, considering the way in which ‘reflective’ issues related to diversity and the assessment process had been some what overlooked.
Older People Case Report Summary

A Cognitive Behavioural Intervention with a 68-Year-Old-Man Presenting with Distress Associated with a Longstanding Tendency to “Fantasise”

Reason for referral
Mr Jensen (68) was referred to the Community Mental Health Team’s (CMHT) Psychology service, by his Psychiatrist for assessment of his suitability for cognitive behavioural therapy (CBT) in addressing his longstanding symptoms of anxiety and low mood.

Presenting Difficulties
Mr Jensen expressed concern about his longstanding tendency to “fantasise”, by which he referred to vivid daydreams usually centred on gaining admiration from others (something he generally avoids for fear of rejection) or ruminating over past grievances. Mr Jensen felt the “fantasies” were worse at times when he was feeling anxious, low or frustrated and believed that they hindered his capacity to have a reasonable and controlled mind. He also feared that confronting others (even imaginarily) was ‘unreasonable’, signifying a potential loss of control. He would subsequently chastise himself for engaging in such behaviour, which typically led to frustration, low mood and further “escapism” through fantasising. Although Mr Jensen’s difficulties were longstanding, they had worsened following his retirement several years ago.

Assessment
Information on Mr Jensen’s background history and current relationships was accessed through use of a clinical interview across three sessions, in conjunction with referral to psychiatric notes. The Geriatric Depression Scale (GDS) and Hospital Anxiety and Depression Scale (HADS) were also administered, identifying clinically significant levels of anxiety (HADS) and mild depression (GDS). An individualised outcome measure was also designed, to provide a baseline for the frequency and levels of distress associated with the ‘fantasies’, which highlighted Mr Jensen’s feelings of guilt surrounding the impact of the these on his relationship with his wife. A risk assessment was undertaken to assess the risk of harm to self and others, whilst also excluding possible cognitive decline and dissociative states.
Formulation
Mr Jensen's difficulties were formulated within a cognitive model, drawing upon cognitive models of personality and self esteem within the context of later life. Here, Mr Jensen's core beliefs concerning his unacceptability/inferiority/stupidity and perceptions of others as critical/humiliating were hypothesised as a response to the absence of positive environmental inputs in his childhood. Thus, in an environment where displays of 'stupidity', emotion and assertion were typically greeted with dismissal/rejection, Mr Jensen developed assumptions pertaining to the importance of emotional/interpersonal control, rendering the fantasies a compensatory strategy or safe forum for both receiving positive inputs from others (through imagined admiration) and enacting confrontation without the risk of rejection. Experiences where rejection or failure to enact strategies was threatened/occurred (e.g. loss of employment/retirement/others violation of personal standards) and associated experiences of emotional distress led Mr Jensen to experience distressing negative thoughts pertaining to himself as irrational/unreasonable and subsequent feelings of guilt. These feelings and their associated appraisals of unacceptability in turn maintained the need to seek solace in fantasies. Throughout the formulation issues pertaining to retirement and later life were considered as possible precipitating and maintaining factors.

Intervention
Mr Jensen sought a practical approach toward addressing distress associated with the fantasies. As such, in line with current research findings and government guidelines a time limited cognitive behavioural intervention was undertaken. The primary focus of this work was in facilitating Mr Jensen's capacity to identify and manage emotional distress, thus reducing his reliance on the "fantasies" as the sole means of emotional regulation. Initially, we also experimented with methods of exerting control over the content and duration of the fantasies, before moving on to challenge associated dysfunctional underlying assumptions pertaining to the importance of emotional control and associated negative automatic thoughts, through use of cognitive restructuring techniques.

Outcome
At the end of our work together, Mr Jensen felt less pre-occupied with, and distressed by, the "fantasies" and had begun to challenge some of his "black and white" standards. As such, the self-devised outcome measure highlighted improvements in experiences of frustration, anxiety, shame and guilt in relation to the "fantasies". Whilst there had been no reduction in the frequency of the fantasies themselves, Mr Jensen described that they were impacting less upon his relationships with others. His scores on standardised measures had also improved.
albeit minimally, GDS and HADS anxiety scale scores remaining within the clinical and mild clinical ranges respectively.

Reformulation
The limited outcome of the intervention alongside the longstanding nature of Mr Jensen’s difficulties led me to reformulate within a psychodynamic framework. Here, I drew upon my observations of Mr Jensen’s difficulty speaking about emotions within our sessions together. I also noted that he tended to experience me as ‘critical’, often chastising himself as “stupid/lazy” after reportedly forgetting to complete his homework tasks. Within the reformulation I considered pertinent object relations prevalent within Mr Jensen’s current and past relationships alongside the therapeutic relationship itself. Primarily, I focussed on Mr Jensen’s experience of a critical, blaming and emotionally unavailable mother, linking this to psycho-dynamic understandings of the super-ego, the psychic structure developing from childhood internalisations of parental notions of unacceptable behaviour. Thus the fantasies and associated behaviours came to be considered as defensive mechanisms mediating distress elicited through intra-psychic conflicts. Recommendations for future psychodynamic and longer-term cognitive work were discussed.

Critique
In reflecting upon the intervention, I considered whether it may have been more beneficial to consider factors related to aging to a greater degree within the intervention. I also considered the dilemmas associated with whether to undertake time limited versus longer-term interventions, justifying why I felt a time limited piece of work was appropriate at the time of assessment. Finally, I reflected upon how invaluable supervision had been throughout my work with Mr Jensen, providing a forum for age related and inter-generational parent-child object relationships in the client and therapist alike. I subsequently, considered the benefit of incorporating psychodynamic understandings alongside cognitive intervention approaches, aiming to make further use of my affective responses to client communications and furthering the formulation.