

The Carers' Journey: Exploring the Experience of Informal Carers of Patients with a Primary Malignant Brain Tumour

A Project Funded by the Surrey, West Sussex and
Hampshire Cancer Network (SWSH)

Dr Anne Arber

Nicky Hutson

Professor Sara Faithfull

Address for Correspondence:
Faculty of Health and Medical Sciences
Duke of Kent Building
Stag Hill Campus
University of Surrey
Guildford
A.Arber@surrey.ac.uk
N.Hutson@surrey.ac.uk

August 2007

Contents

Acknowledgements	4
Project Team	5
Executive Summary	6
1: Introduction	9
Review of the Literature	11
Quality of life for carers	11
Importance of relationships.....	12
Support for PMBT patients and carers.....	13
Obtaining information.....	13
Support from specialist staff	14
Interventions.....	14
Background to the Study	15
Principle Aim:	16
Objectives of the research:	16
Methods.....	16
2: Getting the Diagnosis	18
Events leading up to diagnosis.....	18
Reacting to the Diagnosis.....	23
3: Gathering Information	28
Searching the Internet	31
4: Emotional and Practical Support	34
Finding a relationship with someone who can help	34
Locating the right support from within the family and friends network.....	37
Tensions in family and friends relationships	38
Organising Support.....	40
Support from community services	41
Support from Hospice and palliative care.....	43
Other sources of support	46
Support needs for the future.....	48
5: The Caring Role	51
Becoming a carer	51
Dealing with Short Term Memory	54
Changeable moods and personality changes.....	57
Safety and Mobility.....	59
Tiredness	61
Patient's Attitude.....	63
6: Surviving and managing	65
Carer's Employment.....	65

Finances.....	67
Claiming Benefits.....	68
Support from utilities companies	70
Impact on Carer’s Health.....	70
Impact on children.....	72
7: Carers Coping Strategies	75
Managing communication.....	75
Specialist counselling services	76
Having Time Out from Caring.....	78
Facing the Future.....	80
8: Discussion	84
To what extent are carers’ needs identified?.....	84
How do carers access information and how helpful do they find it?	85
What concerns do carers have?	86
What coping strategies do carer’s utilise?.....	88
Conclusions	90
Recommendations	91
Audit of case notes of patient’s with a primary malignant brain tumour	93
Introduction:	93
Audit Objectives:	93
Method:	93
Data collection	94
Location of care.....	94
Patient Demographics and diagnosis	94
Who was the main carer for the patient in the community?	95
Illness trajectory: symptoms requiring palliation.....	95
Place of death	98
Place of Death	98
Conclusion.....	99
References.....	101
Appendix 1 Discussion Guide	103
Appendix 2 Research Methods	105
Appendix 3 Participants Information Sheet.....	107
Appendix 4 Consent Form	110

Acknowledgements

We are very grateful to the SWSH Cancer Network who funded this project. We would like to acknowledge in particular Ben Thomas and Lorraine Sime who supported us at every stage of the project.

We are indebted to the carers, who freely shared their experiences, and willingly participated in the research.

We also gratefully acknowledge the co-operation and support of the staff at the Royal Marsden Hospital, without whom this research would not be possible.

Project Team

Dr Anne Arber
Dr Patricia Brayden
Professor Sara Faithfull
Douglas Guerrero
Nicky Hutson
Dr Caroline Lucas
Marek Plaskota
Dr Frank Saran
Lorraine Sime
Dr Kay de Vries
Sally Wilson

Executive Summary

Family caregivers are increasingly important as care moves from the hospital to the community. Providing care in the home for people with a primary malignant brain tumour (PMBT) is challenging due to the physical, cognitive, behavioural and social changes associated with such a condition. Furthermore the prognosis of patients with a PMBT is very poor, although increasingly there are long term survivors. The report is divided into two sections. Section 1 is a report on the empirical research carried out to explore how informal carers are coping with caring for a family member with a PMBT. In particular the study is concerned with how carers' needs and concerns are identified, their access to information, the emotional and support services they receive and the coping strategies they utilise to cope with significant functional, cognitive, behavioural and social changes. Section 2 is a report of the audit of the case notes of patients with PMBT, to identify the uptake of services, symptom profiles and caring problems.

The research uses a grounded theory methodology involving 22 in-depth qualitative interviews with informal carers. The sample consisted of 17 spouses and partners, 2 daughters, and one son, mother and father. 17 of the carers were under the age of 60 years. The data was entered in to the computer software package Nvivo and coded and retrieved. The principle of constant comparison was used to analyse the data, resulting in the generation of six themes.

The findings identify the carers' journey as an emotional and psychosocial experience that is at times completely shocking, baffling, overwhelming but also rewarding. Although the concept of a 'journey' is displayed in a linear fashion it is important to point out that the journey is circuitous rather than linear and different milestones in the journey may be visited and re-visited at critical moments during the caring career. Six themes are identified, which are grounded in the data namely: getting the diagnosis and the realisation of what is involved; preparing oneself and gaining knowledge about PMBT by gathering information; enlisting emotional and practical support to sustain them on their journey; adapting to the changes in the person being cared for that cause changes in the caring role; surviving and managing, and strategies of coping.

The findings identify the lack of a proactive assessment of carer needs separate to the person they care for by community professionals. Many carers were reaching a point where they couldn't cope before accessing support. This was sometimes because they felt guilty about

leaving the person they cared for or they were unhappy with the quality of social services support that they were offered. Carers have a significant need for information to help them manage cognitive and behavioural problems associated with changes in the person with PMBT related to their personality and other social changes. They also had difficulties in managing and preventing falls. Carers tended to employ common-sense strategies when dealing with personality and cognitive changes. Carers also had problems in understanding and managing the fatigue and apathy experienced by the person with PMBT. Carers would benefit for more practical support in managing cognitive, behavioural difficulties, fatigue and apathy. Although families, friends and neighbours gave a great deal of support to carers there were some tensions in relationships with the extended family and this was related to personality and cognitive changes that family members found difficult to accept.

Most carers agreed that their ability to cope was improved if there was the possibility of taking some 'time out' from their caring role. Carers who were coping with other dependents, such as other chronically sick family members and school age children, had difficulties having time out from caring. In these situations the emotional and physical health of the carer could be affected.

Many carers were searching for a significant helping relationship to sustain them in their caring role. Either a health care professional such as a Marie Curie nurse, a clinical nurse specialist (CNS) or an experienced carer who could guide them in their caring role, signpost them to services and help them develop the skills of caring. Carers highly regarded the opportunity to talk to other carers who were in the same position as themselves.

The audit of 70 case notes of patients with PMBT over a period of one year, reveals that assessment of carers needs are not routinely documented in patient's notes by specialist palliative care staff. Problems such as fatigue and tiredness appear to be rarely documented with only one patient having this symptom identified in case notes. Yet this is known to be a prominent symptom in patient's with PMBT. Perhaps carers are more aware of the problem of fatigue and report it more than patient's do. This is something that needs further investigation. There also appears to be little use of patient support groups and this may reflect the availability of such groups, or problems in using these groups due to mobility and cognitive problems. Similar to the findings of Faithfull et al (2005) only 24% of patients used day care services. Local variation was evident in the time between diagnosis and palliative care referral; with a median of 66 days at The Princess Alice Hospice, 71 days at St Catherine's Hospice, 46 at

Woking Hospice, 106 days at Phyllis Tuckwell Hospice and 105 days at the Beacon centre. This may reflect local variation in CNS provision and referral pathways in the acute setting.

Recommendations for practice include:

- It is imperative that all treatment centres have a hospital based CNS in Neuro Oncology, as this role makes a significant difference to the quality of information, support and referrals that patients and carers receive
- Identification of a key worker in the community who takes responsibility for assessing carers' needs and providing packages of support
- Training for carers in managing behavioural and cognitive problems, managing falls, fatigue and managing medication in particular steroid therapy
- An appraisal of the training needs of community palliative care nurses and district nurses in providing carer support, managing fatigue, and managing cognitive, behavioural and personality changes

1: Introduction

Primary Malignant Brain Tumour (PMBT) is a rare disease with a very poor prognosis. People with a malignant brain tumour have a severely restricted life span with a median survival of about 12 months. Cognitive impairment, alterations in functional status and the presence of neuropsychiatric symptoms are the most common problems associated with PMBT (Sherwood et al 2004). Cognitive changes can result in short term memory loss, reduced attention, personality and mood changes (Weitzner 1999). There may also be social and emotional difficulties such as agitation, anger and aggression as well as physical problems such as fatigue, apathy, headaches, seizures and sensory changes. The many complex and challenging changes associated with this condition require considerable adaptation by both the person affected by the brain tumour and their family. Carers of people with a PMBT face a unique set of circumstances involving many caregiving demands such as giving physical care but also providing emotional support. Carers face having to develop new skills, to make many adjustments to their dependent's disability and to search for good quality support for themselves as well as their dependent if they are to maintain an acceptable quality of life.

There are around 3,000 new cases of PMBT in adults in England and Wales with around 2,500 deaths each year. The poor prognosis associated with this condition has been consistent for the past twenty years and it is one of the few cancers where improvements in prognosis have not been achieved over time (Guerrero 1998). Having said that there are people with PMBT surviving over many years and this is likely to continue in the future as more effective medical treatment becomes a reality.

This report has two sections:

Section 1: presents the research carried out with 22 carers of people with a PMBT. This work was conducted by Dr Anne Arber the Principal Investigator and Nicky Hutson the Research Fellow.

Section 2: presents the results of the retrospective audit of 70 case notes over a period of one year, which identifies the range of services that patients access, the symptoms they experience and any information on carers needs that are documented. This audit was conducted by Professor Sara Faithfull the Co-Investigator and Marek Plaskota, Research Nurse.

Section 1

Report of Research Project Interviews with Carers

Review of the Literature

Family caregivers are increasing important in the context of chronic health problems and cancer care, as care moves from the hospital to the community. Although various services have developed to support people at home a great deal of community care is given by family members, as well as by friends and neighbours. In the shift from a philosophy of care 'in the community' to that 'by the community' the importance of a discourse of 'informal care' has emerged (Heaton 1999). In this report the terms home carer, informal carer, family carer and caregiver will be used interchangeably to identify a family member or spouse caring for someone with a PMBT in the home.

Providing care in the home is very demanding, particularly where people with PMBT are concerned as there are physical, cognitive and behavioural alterations that can make enormous demands on the carer. Research has demonstrated that family caregivers of people with chronic illness can suffer with emotional and physical health problems that are cumulative over time. For example it is not unusual for caregivers to feel fatigue, have poor sleep patterns and receive insufficient support. In this literature review issues related to carers quality of life such as the demands of managing emotional problems, anxiety and depression will be discussed. The importance of factors which protect the carer will also be explored in particular the quality of the relationship between the person with PMBT and the carer. The availability of services for the carer such as access to good quality information and the assessment and identification of carer's needs and subsequent support by health care services will be critically explored.

Quality of life for carers

In an interview study of 95 caregivers of people with PMBT Sherwood et al (2006) found that two thirds of the people being cared for had problems with short term memory and had difficulties making decisions. The most commonly experienced neuropsychiatric symptoms were depression, irritability, night time disturbances and apathy. They found a link between the care recipient's neuropsychiatric symptoms and higher levels of depression in the caregiver. In particular, difficulties are reported in relation to the palliative nature of PMBT, and the patient's poorer physical health compared to those who have a curative cancer (Borneman et al 2003).

Poor cognitive functioning has been linked to high levels of stress and anxiety in the carer (Pinquart & Sorensen 2003). In one study cognitive dysfunction was evident in 50-80% of patients at the time of diagnosis (Tucha et al 2000). Neuropsychiatric symptoms include anxiety, irritability, anger, apathy and hallucinations (Klein et al 2001). Managing such symptoms can be time consuming and require limitless amounts of patience. There is also the need for the carer to take responsibility for arranging supervision if there are worries about safety. Time out from caring may be difficult depending on care requirements and the presence of other dependents. There can be problems with the carer continuing to work outside the home, which may cause financial difficulties and this is a serious factor in the ability to maintain a satisfactory quality of life. In an interview study by Thomas et al (2002) of thirty two carers of people with cancer, carers were found to be engaged in care work tasks that required a redistribution of the division of labour in the household. Thus the care demands in the household increase not only for the carer but also for other family members, as work in the home is redistributed across other family members.

Importance of relationships

A number of protective factors are mentioned in relation to the caring role. In particular, the quality of relationships with partners, family and friends who enable stability over time for caregivers. In one study of 25 patients with PMBT and their spouses, the level of awareness of their situation was evaluated (Salander and Spetz 2002). In the study by Salander and Spetz fourteen couples were satisfied with how they were dealing with the changed situation. They seemed to evaluate the situation the same way as their partner or spouse and were mutually aware that death was on the agenda. Salander and Spetz (2002) called this 'living despite the awareness of dying'. However, the carers who had the most difficulty were those whose spouse suffered from cognitive problems or were disabled from the onset of the disease. In this situation, the patient tended to be over-optimistic about the future and did not want to talk about their spouses' worries and concerns. This often resulted in 'drifting apart' according to Salander and Spetz as worries were not shared and agreement on coping was perceived as absent by the carer.

In some studies it is reported that carers and patients have more satisfying relationships despite the cancer experience (Thomas et al 2002). However, carers still reported struggling with discussing recurrence of the cancer and issues related to death. In other studies carers report a loss of intimacy in the relationship, which led to loneliness and a feeling of isolation for the

carer as they may not be able to share their feelings with their partner (Eriksson and Svedlund 2006). Ericksson and Svedlund also discuss how carers experience illness as an ‘intruder’ who demands attention. They found that carers, by giving priority their own concerns, sometimes felt feelings of shame. Thus the illness ‘intruder’ can severely disrupt family relationships and intimacy.

Support for PMBT patients and carers

People with PMBT suffer from cognitive impairment and they may not be realistic about their ability to manage independently. Problems with memory and the inability to initiate activity may mean that there are problems in relation to adhering to treatment, self care activities and performing tasks in the home (Fox et al 2006). Furthermore, on the surface, people with PMBT may appear ‘normal’ and the impairment may be subtle and only detected by close family members. The difficulties that arise include problems in planning, decision making and managing different tasks. These problems may be misunderstood by other family members and friends.

In a study by Stoltz et al (2006) the experience of support was explored with 20 family carers. In this study carers identified support as having their situation recognised by others. Non support was identified where carers felt overwhelmed by responsibility and felt alone in their caring and unable to attract attention to their situation. In particular having to pursue access to services, being met with thoughtlessness and having problems accessing help with their caregiving, all caused distress. They identified the 24 hour nature of caring and assuming responsibility for care, and felt in great need of advice. The family caregivers were searching for someone to share the responsibility with – a lifeline. This person cannot be anyone it is someone they feel they can trust. Family members needed to feel able to depend and rely on the supporter regardless of whether they are a trained professional. This is very important, as family carers may experience difficulties in asking for help. So having a trusted person to share responsibility with was deemed very important.

Obtaining information

In one interview study of 39 patients and 35 relatives in relation to terminal cancer, information giving was one of the most important areas identified, in particular, the issue of prognosis and hope (Kirk et al 2004). However many people reported distress at how the information was given, such as being given to soon or when they hadn’t asked for it. The second issue found to

be important was the need for a hopeful message such as the possibility of cure or longer life, or continued care and 'not giving up'. Having hope dashed by insensitive communication was experienced very negatively. Most people, in particular family members, obtained additional information from the internet, friends and support groups. As the illness progressed, the patient and families had different needs. Many patients did not want as much detail about prognosis, and family members talked to health care providers at the patient's request. There is some evidence that the patient and family member did not talk as openly as the disease progressed and this is similar to the findings in Salander and Spetz's (2002) study. Patients focused more on daily living and managing symptoms and relatives were more concerned with prognosis and care giving.

Support from specialist staff

In a study of home-based palliative care, carers identified a lack of attention to their needs by specialist staff (Hudson 2004). It is not clear to what extent carers feel informed and supported about the behavioural and emotional changes associated with having a malignant brain tumour. There is likely to be training needs related to managing behavioural and emotional changes for specialist community palliative care nurses as the problems associated with a PMBT are fairly unique in the context of cancer care. Carers identify the importance of community services being delivered in a way which helps them to achieve important outcomes, such as reducing stress and helping them to cope. Identifying and agreeing outcomes with carers is an important dimension of a nursing assessment.

Interventions

Interventions suggested for caregivers in neuro-oncology include the following:

- Good quality interactions between family carers and health care professionals (Stolz et al 2006)
- Information and psychological support (Hileman and Lackey 1990)
- Education and counselling to help the caregiver manage problems in the home (Hudson 2004)
- Information and knowledge regarding neuropsychiatric symptoms including pharmacologic therapy (Klein et al 2001)
- Tips for employing and using secondary carers

- Neuropsychiatric evaluation to enable interdisciplinary work and improve QOL (Fox et al 2006)
- Cognitive interventions: cognitive training, memory rehearsal, timed reading and verbal mediation (Fox et al 2006)
- Access to physiotherapy and occupational therapy to maintain/improve patient's QOL and give hope (Hackman 2007)
- Couples and family therapy

Evidence for the take up of support services for carers is hard to come by and often goes undocumented in patient's notes. There is evidence that younger carers, women and those caring for patients at diagnosis and the end stages of the disease have the greatest needs (Thomas et al 2002). Furthermore in a recent study involving a retrospective analysis of the medical notes of patients with PMBT, documentation of information related to carers was generally absent (Faithfull et al 2005). The needs of carers with PMBT are likely to be undocumented and therefore remain non-accountable by health care professionals.

Background to the Study

This study aims to fill a gap in the research literature by exploring the specific experiences and support needs of carers of patients with PMBT. Geographically, the research focuses on carers of patients in the Surrey, West Sussex and Hampshire (SWSH) cancer network. This study will provide information on the kinds of assistance and interventions likely to be welcomed by carers of patients with a malignant brain tumour. It will determine the appropriateness and timeliness of information currently available to carers to help them manage behavioural and personality changes, safety issues associated with poor balance, falls, seizures and how to manage their time. It will make recommendations for meeting carers' needs for emotional support.

The research involved in-depth qualitative interviews using a grounded theory approach (See Appendix 2) with 22 family caregivers. The sample consisted of 11 wives and 1 female partner, 4 husbands and 1 male partner, two daughters, one son, one mother and one father. Carers of this group of patients were mostly under 60 years of age. There were 5 carers in their 60s, six carers in their 50s, 4 carers in their 40s, 6 carers in their 30s and 1 carer in her 20s. Of the 22 carers 8 had been caring for their dependent for over two years.

Principle Aim:

The aim of the research is to explore how informal carers are coping with caring for a family member with a PMBT

Objectives of the research:

- To what extent are carers' needs identified?
- How do carers access information and how helpful do they find it?
- What concerns do carers have?
- What emotional and social support do carers receive?
- What coping strategies do carers utilise?

Methods

This study followed a grounded theory approach (Glaser and Strauss 1969) using in-depth interviews with 22 family caregivers to explore their experiences and needs. A topic guide was used (see Appendix 1) and written consent was granted by each participant (see Appendix 4). Ethical approval for the research was gained through the National Research Ethics Service (NRES) and the University of Surrey Ethics Committee. The data was collected and stored in accordance with the 1998 Data Protection Act. Data analysis was completed using NVivo computer assisted qualitative data analysis package, which enabled the data to be coded and retrieved. More detailed information on methodology is included in Appendix 2.

The findings demonstrate how the carers' journey is an emotional and psychosocial journey that is completely shocking, baffling and at times overwhelming; particularly when the diagnosis of PMBT is first confirmed. Therefore the start of the carer's journey is when they and their spouse or family member receive or 'get the diagnosis' and this is the first theme explored. The next theme is preparing oneself and gaining knowledge about PMBT by 'gathering information'. The next theme in the journey is when carers enlist 'emotional and practical support' to sustain them on their journey, such as developing supportive and reciprocal relationships with health care staff and other networks of help and support in the community. Adapting to the caring role is the next theme explored. This is where carers describe how they learn to give care and attention to their spouse or family member and manage difficulties such as short term memory problems, behavioural disturbances, tiredness

and the physical aspects of care. The theme of 'surviving and managing', reports the financial impact on the family, the impact of caring on the carer's health and the well-being of children. The final theme is about 'strategies of coping'. In this theme carers report how they manage communication, seek specialist help and get time off from caring that enables them to get through their journey. Although the idea of a 'journey' is displayed in a linear fashion it is important to stress that the journey is circuitous rather than linear and different milestones in the journey may be visited and re-visited at critical moments during the caring career.

2: Getting the Diagnosis

Receiving the diagnosis of a PMBT was a completely unexpected and shocking experience for all the carers. One carer had an aunt who had died of a malignant brain tumour and she made the connection between her husband's symptoms and those of her aunt prior to the diagnosis of PMBT. A few carers talked retrospectively of noticing changes in their dependent's personality long before any physical symptoms had occurred. For some, the diagnosis was reported as extremely quick, because the person presented more dramatically, with symptoms such as seizures, speech problems, and difficulties in walking and balance.

Events leading up to diagnosis

It seems that none of the early diagnoses were clear cut, as PMBT has many different presentations. For some, the initial symptoms were physical. For example changes in balance and headaches were the first sign that something was wrong:

Well sometime in 2003 it all started. John wasn't well. I noticed it when I was driving because.....he was leaning on me, and I'd say, 'John don't lean on me I'm driving' and then he started walking to one side, and then he had these terrible headaches and we went to see a doctor. His doctor thought that it was something to do with his heart and tested him, couldn't find anything wrong. They decided that it was an inner ear problem. So they sent a letter and we didn't hear for ages, and then there wasn't an appointment for 18 weeks... a couple of the guys in the office said to me take him back to the doctors, so I did...my GP told him to walk to the corner of the room and come back, and he knew immediately what was wrong with him. He looked at me, and said, 'he's got a brain tumour'. He rang his friend who's a neurologist and arranged an appointment the next morning, He had a CT scan, a big tumour was seen, and they operated the next day. (Wife 6)

This carer reports a number of difficulties with her husband including walking, balance and headaches. According to Grant (2004) headaches are the most common presenting feature of a brain tumour. With the encouragement of people from her office she took her husband to their GP. The GP diagnosed a brain tumour and then things moved very quickly. Within a couple of days her husband had a scan and then surgery for what is described as a 'big tumour'.

For the majority in this study, a major seizure was what alerted the patient and carer that something was terribly wrong. In the next data extract the carer reports how his son had a seizure when his wife was being visited by the midwife:

The first thing that happened is we had a new baby and the midwife was round to see it and he had a fit on the floor. The midwife sent for an ambulance. They said he's epileptic,... sent him home and about two days later he had another fit. That's when someone at DGH said we don't think it's epilepsy, he's beyond us, and sent him to the[neurosurgical unit] for a scan. (Father 5)

The carer explains how his son was treated for epilepsy but within a couple of days he had another seizure and was referred to the neurosurgical unit. A seizure is the second most common presenting symptom of a brain tumour (Grant 2004).

In the next data extract the carer reports how his wife had a 'fit' and had displayed unusual behaviour. His wife was pregnant at the time and went on to have a healthy son.

My wife, when she first got the brain tumour was 33 years old, she's now 42 and she was pregnant. She was pregnant in the January and we went out to see her family in South America, had a couple of weeks out there, came back, and within 9 days she had this big fit and the day was very strange. She was doing things she wouldn't normally do. She ran herself two baths. She ran a bath, let the water out and ran herself another one whilst she was still in the bath tub which was unusual, and at the time she was working as a care assistant for blind people so it was quite a shock when I saw this fit. So we called an ambulance and she was taken off to hospital but because she was pregnant they decided to look into what had caused it, and to start with they couldn't find anything and they decided to do a brain scan and the brain scan was abnormal and they said that they wanted to send her for tests at the Neurosurgical Unit. ...I knew there was something obviously terribly wrong. Initially I was very positive as my mum's [tumour] was benign so my reaction was I've been here before, I can cope with this, but as it turned out Rani's was malignant. (Husband 20)

This carer had experience of his mother having a brain tumour however his mother had a benign brain tumour and he contrasts this with his wife's malignant tumour. Rani was behaving in a strange and absent minded fashion running two baths before having the seizure. Also she

had a responsible job as a care assistant, so the unusual behaviour was completely unexpected. Rani has survived many years with her brain tumour and this is a very unusual situation.

Another carer who is a trained nurse describes a family barbeque where her husband Tom started to have speech difficulties followed by a seizure, which she initially linked with a stroke:

We were having a family barbeque and he um, not so much collapsed but he started having trouble with his speech and being a nurse I thought, he's having a stroke as he became quite dysphasic so, um, the family said perhaps he's a bit stressed and so he sat down and within half an hour his speech was ok again, and then he started being sick so we called an ambulance, took him to hospital and nobody was sure what was going on and he then had a massive fit, huge fit... and they sent him for a CT scan, and initially they sat me down and said he has had a massive stroke, which is incompatible with life and he would not survive the night. I though, I just don't believe it. To me, you don't normally have a fit with a stroke, so I... demanded that he be given some steroids because I felt there was more swelling and the doctors agreed... and within 10 hours he started to wake up..... he then had an MRI scan and they picked up the brain tumour.
(Wife 19)

This carer describes a very dramatic situation where her husband, a man in his thirties, is thought to be having a stroke because of his difficulties with speech. However he is not in the usual age group for having a stroke. In the local hospital the carer was given very bad news about her husband's condition; that he would not survive the night. Fortunately she immediately questioned the link between a fit and a stroke and demanded that he be given steroids, to relieve the swelling on his brain. As she describes, following treatment with the steroids, he began to wake up and the MRI scan confirmed the presence of a brain tumour.

Another carer describes a feeling that something was 'definitely not right' with her husband. He had a couple of car accidents with her young son and this had caused her to worry about safety:

I just knew something wasn't right it was really, really weird, because ... had the day off and he had James in the car and he pulled out didn't see because his eyesight was a bit depressed as well and he had an accident and I was like really worried that it was going to happen again, which it did but thankfully James was alright again.... I was driving to work one morning and

I'm thinking and Peter was at home with the youngest one James. He wasn't at school for some reason and I was driving off to work and I was, I had this really like a really big black cloud over me and I thought something's seriously wrong. Even just the accidents because they weren't major ones and I thought he was really uptight, grumpy and everything really not right. I just had to stop the car and pull over I was really, and it is not like me really isn't like me something's definitely not right. I rung my [boss] up and said I can't come.... (Wife 10)

This carer describes how she felt a 'big black cloud' over her and this functioned as a warning sign that something was very wrong with her husband Peter. There had been two minor car accidents, which were unusual for her husband who is a police officer. Also she describes the change in his personality he was up tight, grumpy and nothing felt as it should. She put these incidents, changes and her feelings together and decided that she had to go home and sort things out because she felt something was really wrong with her husband's behaviour. This carer had experience of an aunt who had a PMBT.

Another carer reported a significant length of time living with a misdiagnosis before the brain tumour was identified. The carer describes how his wife went through 10 years of psychological treatment before the tumour was diagnosed:

We weren't quite sure what it was, and we, sought psychological advice and she had psychotherapy... and at one point she was admitted to (hospital).... All along the cause was the tumour. She thought it was something mental, the anxiety... she had had psychological help... it was like opening Pandora's box, it's a scary process when you have to face your issues and your skeletons from the past...it was an osteopath who thought about it. She was having trouble writing and she was concerned that it might be something more and suggested that she went and saw a doctor and from there we went to see a doctor for an MRI scan and they discovered it straight away, and they operated within a week and that's when the whole ball started rolling really...(Husband 21)

In this situation the carer's wife was thought to have psychological problems with anxiety and had been referred for psychiatric treatment including psychotherapy. One of her physical problems was related to her writing skill and an osteopath picked up on this and urged a referral to a doctor. Once the diagnosis was made she was operated on within a week. This situation

points to some difficulties in being investigated, when the presenting symptoms of a brain tumour are related to behavioural and personality problems rather than physical problems.

Another carer talked about how her husband's problems were difficult to pinpoint, but she did say that she had noticed some changes in his personality over time such as a lack of communication:

He went into work one day and a colleague apparently spoke to him and he ignored them. He spoke to him again and eventually got his attention. He had a kind of maybe a blackout. At home he wouldn't speak to me. So I think really, looking back, it had been coming on for awhile. (Wife 12)

This carer reported distress at her husband's lack of communication and she went on to explain that she had felt that there had been something seriously wrong in her relationship with her husband for some time.

Similarly another carer reported the strain that was put on her marriage by her husbands' level of tiredness and aggressiveness even before they realised there was a physical problem:

It was a really, really bad patch like something that we couldn't understand.. because we have lived together for 11 years so when he started acting in a different kind of way not different as in a different personality like more aggressive that I thought it was because he was more tired... I couldn't understand, I couldn't recognise him in a way but in a sort of way you know what I mean it wasn't like a proper different person altogether. So it was just a sort of thing I think it was more the tiredness that his body was dealing with the tumour. Cause he would come back from work and he would just go to bed and then I would get angry because I would say just give me a break with the kids just help me with the bath and normal things like every couple I think and you normally have these issues I think if you have small children (Wife 17)

This couple had two young children under school age. She describes how her marriage had been going through a 'really, really bad patch', which was unusual because they had been together for a number of years. Her husband was more aggressive but also very tired. She describes it as 'acting in a different kind of way' rather than a different personality. This suggests that it is her husband's behaviour rather than his person that she sees as changed. This is interesting as the carer is reporting the changed behaviour but emphasising the integrity of

his person. Even though she couldn't recognise him in one way, he wasn't different altogether, is the way she describes the situation. She put the change down to his tiredness with his body trying to deal with the tumour, but at the time she felt angry about his lack of help with the children. The changes in her husband put a big strain on their relationship prior to his diagnosis of a brain tumour.

Another carer reports how her husband's mobility was the first thing that was affected and his ability to write:

He's got a grade 4 tumour which has affected his mobility, which is for him the worst thing that could have been affected. He's left handed and it's his left side which is affected. The first symptoms really were when he discovered he couldn't write. He was trying to write and couldn't go across the page, all the letters went on top of each other. So he is unable to write and therefore he's unable to do crosswords or anything, or even committee work, which he might have been able to do at home. (Wife 23)

This carer reports on how problems with her husband's writing was the first indication that something was wrong. This was a very devastating situation for her husband because he liked physical activities like playing bowls, was a very active man despite being retired and could no longer do crosswords and charity committee work, which he greatly enjoyed.

Reacting to the Diagnosis

All the carers reported their shock and disbelief when they received the diagnosis of their family member's brain tumour and its associated prognosis. The majority of carers are completely taken by surprise by the poor prognosis associated with a PMBT. The data extract below describes the carers shock at hearing the news of her husband's diagnosis, but this is balanced by attending the specialist hospital for appointments and this brings some order to a shocking and disturbing experience:

Nobody prepares you for the shock. The doctors have said well that's it you know, but all the things started to kicking in from the [specialist hospital] that's very good like your appointments and things, but it's still too shocking. (Wife 1)

Another carer reports how he was in 'complete shock' but found it beneficial to talk with the Clinical Nurse Specialist (CNS) following the bad news of his wife's condition:

I was driving to the hospital, yet again in complete shock and [the CNS] called me in the car and said, 'I must see you, I must speak to you'. I didn't really think that anyone was worth talking to at this stage because what more news could I have. But the [CNS] was very good. He's a lovely man, he looks as if he takes on all of the pain of all his patients and he had the day room prepared. The curtains were drawn and he sat with me and a nurse who just sat nearby (Husband 2).

This carer describes the attention of the CNS and how the CNS was 'lovely' even though initially the carer had felt that it was not worth talking to anyone. Furthermore, this carer reports how he found hope for the future in what the CNS is reported to have said: '*I've been in this game a long time and I've seen people..... different..... nothing is written in stone as far as prognosis goes*'. This gave the carer some hope in a very difficult and shocking situation. The CNS was able to convey his support and empathy for this man's situation.

The carer in the next data extract describes the very bad news she and her husband received from the neurosurgical unit in terms of a poor prognosis:

I said to the surgeon, in front of him, 'how long are we talking about?' First of all I said 'how long do you think he's had it? How can you get something that serious?' He said 'three to four months'. I couldn't believe that. How can it be that bad, but it is a primary in the brain, it's not come from somewhere else. So I asked how long and he said to Jim, 'do you want to know?' and he said 'yes', but really didn't, but said 'yes'. So he said 'well put it this way, you won't be here in a year's time keeping an appointment'. So you assume from that he meant less than a year. Well that was just, phew, I don't know why but I thought all along if they tell me ten years that'll do me. (Wife 22)

This couple have received the news of the brain tumour and then the shocking news of the poor prognosis. It is the carer who asked about the prognosis but before giving a prognosis the surgeon checks with Jim, who agrees that he wants to hear what his prognosis is. This is a big shock because the carer was expecting to hear a prognosis of ten years rather than one year. There was a large gap between her expectation of her husband's prognosis and the news from the surgeon.

For some carers there is bad news on top of bad news. In the data extract below the family were alerted to the gravity of the situation as prior to the surgical biopsy they were told there was a risk of death from surgery:

...you know I suppose one of the big stages for us was before he went in for his biopsy at the [neurosurgical unit] and we were told that there was a small chance that he would not survive. That rather concentrated the mind as we had to talk about funerals and things like that which was very, very distressing at that point because you know you weren't sure if he was going to be around the next day. (Daughter 3)

Although the risk of dying was described as 'small' this family were already thinking about planning the funeral for her father. This was the stage where the family realised the gravity of the situation.

Another carer describes how the surgeon delivered the news in a graduated manner, giving time for adjustment:

It was done by the surgeon ... they do it really well. They talk about it when the person is not quite with it. He hears it but then he needs time to adjust to it. Then later on they mention it again. So it isn't then such a shock. It is a shock but it could have been worse. I spoke to the doctor afterwards. The doctor said that I have, 'I know one patient who has had it for 10 years and he's fine'. The first thing that Ben said when he heard that, 'I will be the exception' and that was his attitude. (Mother 11)

The mother describes how the surgeon breaks the news to her son gradually giving time for his adjustment to having a brain tumour. Ben's mother also had time with the surgeon on her own. The surgeon gave her some hope by describing how one patient had survived over a long period of time. This is a positive message and was one that she relayed to her son who responded that he would also 'be the exception' to the expected poor prognosis.

Another daughter describes how the doctor checks out with her how much she wishes to know about her father's condition:

And she [the doctor] said 'are you sure you want to know this?' And that moment I understood that yeah do you want to know this or not and then we decided we have to play the open game; because if you want to of course there are people who can deal easier with it when they are not open but we just told the doctors 'we want to be straight forward with everything' so that they could share everything instead of being afraid because you might have the worst problem in the world or consider that you have the worst problem in the world but when you face it when your recognise it then you're not afraid any more. So you don't have to hide... and after these three days I realised I

wouldn't change the whole situation back four days ago when we wouldn't know anything at all because knowing makes you much stronger than hiding. (Daughter 4)

This daughter describes how she and her mother and father wanted to be 'open' to the information about her father's condition and she describes this as playing the 'open game'. This enables her mother and father to share everything and to face it. This is the situation of open awareness described by Glaser and Strauss (1969). She contrasts this with hiding from the situation, which is similar to the closed awareness context described by Glaser and Strauss.

In another situation the carer decided to hide details of her husband's prognosis from him following a discussion with her GP:

When [the surgical unit] told us he had a year to 18 months, or told me, I told [GP] and said 'should I tell John?' and we agreed that we shouldn't. As I thought he might give up. He's never forgiven me for that (Wife 6).

The carer explained that her husband found out about his prognosis when he visited the specialist hospital and was told about it by one of the doctors. John then realised that his wife had withheld this information from him and he was unhappy about this. However now the carer reports that, *'he knows everything. He has the copies of the letters from the [specialist hospital] and he's been a lot happier since then as he wants to know what's going on'*. In this situation the carer and the GP had perhaps wanted to protect John by keeping him in a closed awareness about his poor prognosis. This demonstrates the variety of strategies preferred by carers, patients and health professionals when managing issues related to communication of a poor prognosis.

One carer made the point that having time on their own to discuss what her role was going to be with her husband would be helpful:

Thinking back to that day when we had the prognosis and you know heard what might happen, it might have been nice to have known a bit more about my role, to have been seen separately and told maybe what was going to happen to me... I just thought that at the very beginning if there was a carer there just to point out what might happen. It might have been hard to take on board but I think you might be a bit more prepared.... Well whereas we had a normal family life and my husband would help me to do things cos I was working, that's all gone. (Wife 22)

This carer suggested that it would be useful to have time on her own to discuss her role. She suggests that someone such as another carer might initiate her into what the role in looking after her husband would be, and enable her to be 'more prepared'. The division of labour in the house had altered since her husband became ill with the carer doing a lot more household tasks, which were previously shared with her husband. Life was no longer 'normal' and adjustments needed to be made

In summary, the carers reported a wide range of different ways in which the brain tumour presented from mobility and balance problems, speech difficulties, seizures, psychiatric problems, tiredness and irritability. The most complex and long drawn out experience was the psychiatric misdiagnosis which caused untold stress for both the patient and the family. In particular the problems related to personality and emotional changes put a great deal of strain on marital relationships. Overwhelmingly the news of having a PMBT was shocking and completely unexpected for patients and their carers. A number of things ameliorated the shocking news including sensitive communication between health professionals, patients and carers, which conveyed hope. Carers identify strategies to maintain hope such as experiencing doctors and nurses spending time speaking to them and their dependent together as well as apart, and sensitively dealing with questions about prognosis that enabled them to remain hopeful. Although one carer wished to protect her husband from the bad news of his poor prognosis, open communication was favoured by the patient.

Offering words of hope and optimism related to prognosis was found to be helpful and was a buffer to the bad news related to prognosis. The starkness of the prognosis was completely unexpected for many. One carer in particular referred to having an open and straightforward communication with medical staff that enabled the family to face the future together feeling fully informed. Finally, one carer explained how she would have liked more information on what her husband's condition meant for her role as a carer, and she describes how receiving help, preferably from another carer would be helpful.

3: Gathering Information

The carers were asked how they went about gathering information about their dependent's diagnosis in the early stages. Carers explained some of the difficulties they had in taking in information when they were still feeling very shocked and emotional. Information needs were mediated by the carer's emotions and their dependent's physical and emotional needs. Many relied solely on the information given to them by the specialist hospital where their family member was receiving treatment.

For those treated in a District General Hospital (DGH) gathering information was extremely problematic. One person described how she was sent home with no useful information:

We weren't given any information, nothing. We weren't given any help until last year when I kicked up a fuss big time... (Wife 15).

This carer was eventually referred to a specialist hospital and the level of information she received was described as significantly improved. Many carers (18,22,15) remarked on how good the specialist hospital was in providing explanations and written information in contrast to other centres. In the specialist hospital there was also a designated CNS whose role was to provide information and to give support.

In one instance a carer describes how she was given faulty information at her local DGH:

I did have a call from one lady, a physiotherapist from [DGH], who actually, I don't think lived on the same planet as the rest of us. She basically said to me we're going to be discharging my husband, and I said, 'oh ok, so what are you going to put in place to help us?' because I work and I was working full time at that stage, and she said 'well, can't you give you work?' And I said 'I'm sorry but no, I can't give up work', and she said 'well if you give up work they'll pay your mortgage for you', and I said, 'I don't think it works like that', and she gave me all this wrong information that I knew was a load of old rubbish and in the end she said 'well there's nothing much we can offer you' and I thought well great, you know. (Wife 18)

This carer felt incensed with the poor information received from the health professional described above and the lack of consideration of the carers needs. This conversation was reported as unhelpful and upsetting and made the carer feel angry at the lack of insight and knowledge about her and her husband.

One carer describes how she felt confused by whether information was available or not, although she was aware that she may have been given information and not taken it in:

In the beginning I had no advice on what happens to people with brain tumours. The health professionals didn't guide me where to go. I think it was all there but I didn't take it, I don't know (Wife 1)

This carer was very emotional during the interview. Her husband was very ill and imminently dying and his disease had progressed very rapidly. She did not feel able to take in the available information. When carers have a lot of anxiety and worry it is very difficult for them to retain information.

Another carer mentioned the lack of information from the neurosurgical unit when his son was discharged following surgery:

he day they finally said he could leave he scrambled in the car, he just wanted to go, but you're feeling very insecure if anything goes wrong. You've not got a checklist, I wasn't given anything. Just all the Sister said, it was a Sunday night, she said well give us a ring if you've got any problems but I said have you every tried to ring this hospital? I have and you don't get through. Oo, I think you will – I said no, you're telling me what you want me to hear, not what happens... if this had been his first operation I would have been terrified because you get him home, you don't know.....then his wound got infected. I've seen infection, I said this is infected, we've got to do something but our local hospital doesn't want to know and he won't go to them anymore because he's had such a bad experience. (Father 5)

This father reports his insecurity and worry about caring for his son post surgery. He felt that some carers would not understand when a wound was infected or what to do about this. He felt that having a checklist of what to look for following surgery would help him understand his son's needs. This father and son have had a very negative experience at their local hospital and so are reluctant to seek advice there. A recurrent theme in the data is the lack of trust in non-specialist hospitals who on the whole do not know how to deal with a person with a PMBT.

One area that carers felt that they needed help with was the management of medications such as steroids and chemotherapy:

Well he's recovering from being taken off the steroids too quickly I knew it was happening, we'd already been (given an) authorised dose. I didn't quite understand the working of them I guess I need to know a bit more (Wife 12)

Another carer referred to the problems related to steroids and the inability to sleep:

I could have done with a two day seminar on steroids and the effects of steroids. Nobody tells you to begin with they don't make you sleep he didn't sleep on steroids they don't tell you that (Wife 1)

Another carer described how his son would return from the hospital with no recollection of what he had been told by staff about his chemotherapy:

So I would take him to the hospital and he'd go in and I'd say, 'do you want me to come in' – 'no' – 'ok alright', I had to respect that. And then he'd come out and we'd come back and would be querying straight away, 'what do I do with these tablets, what do I do?'and I would phone up and they would say 'oh no, we're not allowed to discuss this with you because you are not put down as a person'. So I think once you have established there is a carer, whatever they are whether they are a parent or a wife, that aspect has got to be sorted. Because you know you are up there usually all day going from one clinic to another and if you're not given the information the patient they know in many cases is not capable of relaying it to you. I came back here the first time with his drugs for the chemo and you had to make it up. I think the dose was something like (). So you had three tubs to open, take the right amount out and calculate the dosage. Now someone in his worse state who couldn't remember what he'd had for his lunch when he got it. I am sure I'm not the only one to come across that. But this time I've gone in and I've seen people like the [CNS] who've got it clear. (Father 5)

This father reports problems getting access to information about his son's treatment. As his son has poor short term memory he was unable to remember how to take his tablets. Initially staff were unwilling to share information with this father until the CNS sorted this out. The importance of the CNS role is a key feature in the accounts of the carers.

Another carer reports how her husband asks her difficult questions about his condition:

The care is all about Phil but I am his sole carer and he asks me a lot of questions. Phil's the kind of guy that will absorb the information and then start firing questions at

me a couple of days later. He says if they've taken the tumour out most of it out why is it going to re-grow? (Wife 8)

In this situation Phil is quizzing his partner about his condition. He is asking difficult questions about his tumour that perhaps puts his partner on the spot. From the carers perspective she identifies that the care is all about Phil rather than the carer. She felt unable to ask questions when she was at clinic because Phil was present and she didn't want to 'get him down' as he had a propensity to moodiness, particularly during his radiotherapy. She was finding his moods difficult to deal with. This woman had two young children under school age.

Searching the Internet

Virtually all carers reported accessing the internet in some ways to search for information. Feelings were mixed about the benefits of information on the internet. One of the main limitations of searching for information presented by carers was that it could be depressing, inflicting more bad news on already worried and anxious carers. Although some of the sites recommended by health professionals were found to be very clear and useful.

Two carers (19,2) reported how helpful the Cancer Backup site was : *'They've got really clear, concise what you need information, what you need to know, it's really good, symptoms, treatments and they go through all the different types of brain tumours'*.

Another carer found a group on the web that offered some hope and optimism related to surviving a brain tumour:

There is a really good website it's called the International Brain Tumour Alliance which is really good that's really, really good. It's all about, because his condition is so devastating and everything. The prognosis is really bad. It is good to find some websites that give you actually hope. And there is some hope there are people who can survive but there are specific things you should do. You have to take specific drugs and things like that (Wife 17)

The internet was also useful to search for information about new treatments for brain tumour:

we've got to go back at the end of March and they will review it again. There's a new drug out that I looked at on the internet that's supposed to be quite effective with radiotherapy and I don't know whether it would be possible for him to have that - if he does have to have another course at some stage but we'll wait and see. (Son 16)

and to find support either through advertised support groups:

He was being treated at the [DGH centre], and it was only through searching the internet that I found out about the support group at the [specialist hospital (Wife 19)

or online support groups:

Hammerout it's a lot to do with Frenchay hospital in Bristol. You can put your story on it. The forums haven't got going or anything but I found it very useful you could write your story just a few lines and then I've emailed and you know in fact I printed all my emails to one particular lady off the other day. I don't know what I'm going to do with this but I'll do something with it all one day. But you can see the shock my shock, her resignation because she was a month ahead of me and then you could see my hopeful bit like at Christmas the scan was good. (Wife 1)

This carer describes how she posted a short narrative about her situation on this website and found it helpful to read what other people had posted and to make contact with other carers by email. She describes her emotional journey in contrast to another carer. For example her shock and the other woman's resignation followed by the carers hope when the scan was good. This demonstrates how she could mirror the reactions of herself and the other carer and identify the events and the emotions involved.

Others avoided the internet, as they were scared about what they may read and the effect on the person they were caring for:

I didn't need to go searching round the net for anything else and I wasn't really in a position mentally at that time to want to do it... and I tried to put Harry off it as well, rightly or wrongly... (Wife 18)

One Health professional suggested caution when searching the internet, and warned of the dangers of using the internet as it can offer false hope and ineffective therapies:

We met a New Zealand doctor at the SH at the beginning and he warned us, he said that there's a lot of people selling you stuff out there that will pretend that they will cure you, there's a lot of phoney treatments and things that pretend to do stuff but they don't actually do it. It can break your heart; it can break your bank. You know, he said, beware, don't, this will kill you, there's no doubt about it, and he was very straight about it (Husband 21)

Another carer expresses her concern with too much information:

There's too much information out there and too many things that you might not perhaps want to read. Too many things. Cancer Research UK's been quite good but again they have warnings up that you might not want to read what's coming and that's then your choice but to find all these things on the internet just completely threw me (Female partner 8)

One carer (Mother 11) had a strategy of filtering information by asking a friend who was a GP to search and to pass on anything which she thought might be useful.

In summary, many carers had important points to make in terms of how information should be presented to them. For some, they wanted the bad news to be titrated, so that they could get used to the shock and poor prognosis over time. Others suggested time alone with the medical team without their dependent present so that they could ask questions that they did not wish to ask in front of the PMBT sufferer. Most carers wanted to hold on to some hope, especially at the beginning as it helped them emotionally. The internet was agreed to be a useful search tool, and nearly all of them had used it, official sites were found to be helpful, but it could produce overly negative and sometimes erroneous information, so it shouldn't be relied upon.

4: Emotional and Practical Support

Support came from a wide range of sources, both formal services and informal support systems such as family, friends and neighbours. Locating the right kind of support could be difficult. A number of people referred to the importance of finding a relationship that was helpful to them both practically and emotionally. Locating the right type of support, especially early on was difficult. Finding an individual or friend who championed their cause had a significant effect on carers emotional well-being and how equipped they felt to deal with their caring role.

Finding a relationship with someone who can help

Finding a relationship with someone who could help was a linchpin for successful caring. This was identified by a patient's daughter. She referred to the caring triangle, which enabled a balance across the demands placed on her mother and father by her father's illness:

Like three of us this triangle it may be something else maybe not more than three people but it cannot be less than three people. When there is a least three people there can be the equilibrium because there is the disease, the ill person, the carer and somebody else that could settle things down. Maybe not directly taken care of the carer but that makes the carer know that he is not alone... It's my family but my mum carries much more responsibility because she obliges herself to. I do not oblige myself. I just do things and that's it so this third somebody is very important (Daughter 4)

Lena describes how she supports her mother who is her father's primary carer. This triangle of care helps to balance the demands of, as she says, her father's illness, the disease and her mother's caring. Interesting Lena describes 'the disease' as an entity in its own right a fourth element in this situation. Her supportive role enables an equilibrium across the many demands on the family. Interrupting her university studies to return to the family home meant her mother was able to go out and earn a living to keep the family solvent.

One of the most important aspects of locating support was finding an individual that carers could rely on, and who was there to support them, rather than their dependent. This was identified by a number of the carers interviewed. In the next data extract the carer describes how she found someone in her local carers association who championed and supported her and her family through the complex benefits system; enabling her also to take some time out:

And they got () carers in touch with us, which was Mary Wilson and she's been fantastic and she has given me all the help that I need. She's contacted other people for me, she's explained things, she's helped us with our benefits, as we weren't getting loads of stuff and she helped us and she gave us all the information and she's got me into days like relaxation days. Every so often I get a day when I can go off and get my dinner cooked for me and I have a massage and I talk to other carers which is fantastic. But before then we had nothing and we were told nothing. We just plodded along coping on our own... (Wife 15)

This carer had four school age children and her husband was disabled by his brain tumour and had limited mobility. Finding the support from Mary Wilson was described as fantastic for this carer as she was able to guide her in relation to access to benefits, put her in touch with people who can help and most importantly enabled this young mother to get time off from caring. The carer contrasts the situation before finding this valuable contact as them just plodding along and coping alone. Not feeling alone in the caring situation was very important and this rested on the quality of the relationship with a helper who could give the carer support from inside or outside of the family.

Another carer described how the Marie Curie nurse was someone she could rely on, a 'Mary Poppins' figure:

The Marie Curie Day Nurse.... she was just like, it is like Mary Poppins arriving (laughs). You know she's a very, very good person. Nothing was too much trouble you know. We didn't do much took the dog for a walk. I felt that I could go out walk and walk and walk you know but you've got to be like this for now and I know that and I'll give up anything for now (Wife 1)

This carer describes her complete trust in the Marie Curie nurse and this was highly rated. She immediately took to this person who like Mary Poppins could sort things out and perhaps settle things down. The quality of this person was that 'nothing was too much trouble' for her. She was able to convey her caring credentials to this family and it enabled the carer to feel she could leave the house and have time out walking the dog knowing that her husband was being well cared for while she was out. This 'respite' for the carer meant she had some time to herself and felt free to 'walk and walk and walk'.

The carers assessed the support services that were allocated to them and at times the quality of support was perceived to be lacking. Locating the right type and quality of support was an issue

for many of the carers. The quality of support from social and other services differed from area to area, which is identified in the next data extract:

I had a sitter today a person who was arranged by a company called Prospero, which is a support for carers, but I couldn't have left him with her. Cause she had no idea, she well I couldn't have left him with her (Wife 1)

This carer had a terminally ill husband who was now bed bound, very confused and was dying. The carer was not happy to leave her husband with the 'sitter' as she made the assessment that this person would not be able to cope with the demands of the caring situation. Therefore although support was available in terms of a sitter being allocated, it was not helpful as the carer did not feel safe to go out and leave her husband with this person.

Another carer describes the importance of knowing the person providing care and ensuring that they identified themselves clearly:

You can get volunteers but it's a bit like the district nurses, some of them are nice, some of them are clued in, but some of them turn up and, one came on a Saturday morning, I hadn't seen the woman before, her uniform was covered by a coat. She said she was from Church Road, I didn't know what that meant, I wasn't sure if she was a Jehovah's witness, and it was only when she said 'have you someone in there who is terminal' that I realised she was actually a nurse, because as I said we had deferred them from weekends (Husband 2)

This carer describes a break down in communication about the needs of the family and community support at the week-end. Crucially the person who turned up at the house unexpectedly did not introduce herself clearly. The carer could not identify her as a nurse as her uniform was covered by a coat. Embarrassingly, he thought this person was a Jehovah Witness. Furthermore, there had been a decision to defer from visits at the week-end. So this visit was inappropriate and left the carer thinking that the community nursing services were disorganised.

Carers strive to develop good quality and appropriate care for their dependent. Most importantly they identify the importance of a good relationship with someone they can trust. The complexity of the caring situation is illustrated by the different levels of support staff that carers have to deal with. They place a great deal of emphasis on the ability of the carer to give

care, their skills, but also their acceptability as caring people who are available at the right time to give appropriate care when it is needed.

Locating the right support from within the family and friends network

All carers found a great deal of support from friends, family members and neighbours. Having someone they could confide in and talk to was highly rated. However, at times the support from their family and social network could be difficult as tensions could arise through perceived insensitive comments, thoughtless remarks, a lack of practical help or no contact from previously close friends. One can only surmise that some friends and family members found the whole situation very difficult to comprehend and perhaps were frightened by the changes in both the person who is ill and the family. For some, the behaviour of family members and friends could be a source of anger and distress for the carer.

In the next data extract the carer had a friend to turn to for support. Her friend was also caring for his wife who has Alzheimer's disease:

This is a book a friend gave me. He's a carer too. His wife has Alzheimer's. Peculiar title [Selfish Pig's Guide to Caring] it's a book....he goes to a carers meeting to do with Alzheimer's and he's out of his depth a bit with his wife. He really doesn't know quite what should be done and they were recommended this book. So in fact he bought it for me because we tend to talk to one another because although it is different caring, different outcomes and everything we.....other carers understand and when you say certain things, which you can't say, I find, or don't feel you can to friends or family who've got no knowledge of what it is like to be a carer. (Wife 23)

This carer identifies the importance of having a friend, someone outside of the family situation who understands what it is like to be a carer. Her friend has bought her a book, which was recommended to him by his carers group. The carer had the book visible on the side table during the interview. She has observed that her friend is 'out of his depth a bit' with his wife. However her friend is someone she can talk to who most importantly understands what it is like to be a carer.

Likewise a daughter described the importance of having a close relationship within the family, in particular to support her mother who is her father's main carer:

When I came here she said after two days she said for the first time I've managed some sleep. So because when there are two people one of whom is sick you're as if on your own you know to take even to talk to share your worries and things like that. And I'm sure that you need a closeness not a psychologist or a psychotherapist or anything. You need something of your own kin or a friend maybe but something really close and yeah so it is much easier when we're together (Daughter 4)

Lena describes how you need a close relationship rather than psychological services. This is a tight knit family group originally from another European country. To Lena and her family the emphasis on support from you own 'kin' or a close 'friend' is extremely important, so that there is a 'togetherness' around caring and support. When Lena is there her mother can get some sleep and share her worries and fears. In this situation she describes how there is no need for counselling or psychological services.

Neighbours were also a useful form of support. In the next data extract the carer could rely on her neighbour when she went out to work:

They've been wonderful. They're both St John's Ambulance trained as well which is just wonderful. They all pop in and see him, and John's got their numbers on his phone if he needs them... so neighbours have been really good.... (Wife 6)

This carer's neighbours were able to keep an eye on her husband and most importantly he could ring them if he needed help. This gave a great deal of reassurance to this carer. This type of practical and neighbourly support was highly evaluated by carers. However there was some tensions reported in relationships with friends and extended family members, which are discussed next.

Tensions in family and friend's relationships

One male carer felt under some pressure with demands for information from his wife's family. Tension with in-laws was a factor in a number of the caring situations:

Certain relatives, Poppy's sister actually who will probably be here in a minute, tends, she's a head teacher at a school. So she's used to getting the answers she wants when she wants. At times she has crossed examined me over what do they say about this, what about this, about this, about this.....so much so that we fell out at one point because she rang up one morning at 7 o'clock in the morning just to see how Poppy had

been over night and bombarded me with questions and I said 'that's six questions, which one do you want me to answer first?' (Husband 2)

This carer describes how his sister-in-law is demanding information about her sister's condition. He describes how they fell out when she was bombarding him with questions early in the morning. Family members have difficulty understanding the pressure the carer is under and how questions and disturbance early in the morning causes further tension and worry for the carer.

Another carer referred to resentment within her husband's family about the attention given to her husband:

Tom's family, well it's quite complicated really.... He's got a sister who I feel, it's stupid to say, but I think she is almost jealous of the attention Tom has had since he has been ill.... Also Tom's parents have recently moved from Sussex down to Dorchester and Tom was hoping they would move nearer to here to help but they haven't. It's just a very difficult situation (Wife 19)

Illness in a family can change family dynamics and these are complex changes that families are adjusting to. This carer is reporting resentment from her sister-in-law in relation to the attention given to her brother within their extended family. There can also be expectations of help from family members that remain unexplored such as her mother and father-in-law moving nearer to help.

Another carer reported how they were planning on moving nearer to her own mother but she had a difficult relationship with her in-laws:

Yeah hopefully it would be easier than up here because my mum gets the bus all the time. His family doesn't help they haven't been supportive but that is another story. It is a sore subject really (Wife 10)

This carer reports how her own mother provides a great deal of support and visits her and her family regularly, but her husband's family in contrast have not been helpful or supportive. Another carer (Carer 14) also had a difficult relationship with her father-in-law and had limited contact with him. The tense relationship between carers and in-laws requires further research as this theme was identified in three out of twenty two interviews.

In the next data extract the carer describes the different ways that friends have reacted. She explained that some friends have difficulties handling the change in her husband:

Some friends have been good some friends haven't been in touch at all. They can't handle it, can't handle the change in Matt. I mean there is a terrific change but he's still Matt he's different if I could and Sian [adult daughter] and I used to get quite angry because in a way we had to cope with it. People are very strange. (Wife 1)

This carer identifies the issue of how her husband has changed, how she and her daughter Sian have to cope with this change but some friends find this difficult and have lost touch. This makes the carer feel angry because she is coping with a difficult situation and some friends do not get in touch.

Another carer explains how relationships with her three teenage girls can be difficult particularly in relation to them helping out with household tasks:

'I don't do washing up' she said so you know it's clear, although ... I don't like to do them down ... because to a certain extent I mean she coped ... she [daughter] downloads stuff for him... tonight they'll be watching Top Gear. She down loaded that and they watch that together when I'm not there. And then Jane she has him watching 'can we watch Coast together tonight' you know ...Cathy in a way not a lot that she will really do with him. And somebody said that she is in denial but I'm wondering if we're all in a kind of denial. (Wife 12)

This carer doesn't want to criticise her children because they are supporting their sick father by downloading his favourite programmes and watching them with him. However one of the girls is not doing anything much with her father and this carer considers how her daughter is in 'denial' but extends this description to the whole family, 'we're all in a kind of denial'. Carers and family members use a denial like mechanism as a coping strategy, which Salander and et al (1996) call avoiding and this is a common coping strategy used by people with cancer and in this study also their carers.

Organising Support

Formal support services included primary care services, hospice and palliative care services, social care services, and voluntary services. Carers had a vast array of potential support to

draw on. Some carers reported a very organised approach to care work taking the initiative, orchestrating and making contact with support services themselves. Others appeared less organised in their care work calling on support as and when it was needed in an ad hoc fashion. Again, carers had mixed experiences of how, what and when they accessed support services.

Support from community services

One carer reported very good support from her GP:

My GP ... he's a wonderful doctor. And after came home he used to come round at least a couple of nights a week after surgery to see how he was, he'd ring up and say do you want to put the kettle on, I'm on my way.... He's been my doctor for 15 years now but he's a lovely man, I don't know what I'd do without him. (Wife 6)

This carer has a very good relationship with her GP over many years and he was the person who initially diagnosed her husband's brain tumour. This situation of such a supportive and personal relationship with the GP was unusual in this study and this is considered a deviant case. The carer in the data extract below had asked her district nurse about support in the home and she was offered respite care:

So I asked my district nurse and she said 'well he can always go into respite' but he'd only just come home, and I said, 'I want him home with me', I couldn't you know, I want him here and I owe him that...' (Wife 1)

The respite care offered was not a solution for this carer as her husband had only recently been discharged from hospital and she wanted him at home with her. She felt a commitment to having him at home where she could care for him. It seemed that carer assessment was not comprehensively addressed by the community health professionals and the solutions offered to carers were sometimes inappropriate to their needs, as an 'off the shelf' offer of help rather than a consideration of needs.

Only one carer describes having a 'care manager' and this is an example of an organised carer who was very informed about what services were available to her:

Yes in fact our Care Manager has been able to organise, well she's written me a letter to say I've got something like sixty hours carer's time between when it was issued, which was I think February, between then and September. She says I'm to use that and

it is for somebody to sit with him. I can either use it on a regular basis a couple of hours every Tuesday or whatever it is. Or I can save it up and have a day out or longer time. Well that's all very well but I don't know any of these people and I feel very uneasy about just saying yes, a complete stranger can come in. He may not like them.....(Wife 23)

There are two issues described by this carer; one is related to 'a complete stranger' who will be coming to sit with her husband and; secondly this arrangement must be acceptable to her husband as 'he may not like them'. This shows the complexity of negotiating real help in the home between the needs of the carer to have time out from caring and the needs of the person being cared for. This carer is concerned about having someone in the house that she doesn't know who may also not be acceptable to her husband.

Another carer speaks about her disappointment with the help provided through social services:

*I suppose I am disappointed in Social Services – you know, I know that it's hard to find great people who are really interested but you know it just seems a shame that my father who is a bright guy, is spending his last days with people who,(sighs) who, who, aren't very interesting for him and um, well, I know it sounds silly but my mother was a bit upset when the carer came to see them and he wiped his nose on his sleeve and yet we are all so careful about germs at the moment and you know it just was like, ooo, I know it's a shame isn't it? I suppose it's not their fault but they say they'll come at a certain time and they come a few hours later, or they don't turn up at all. It's one of those things, it's just a shame that you have to spend your last days like that.
(Daughter 3)*

This carer is pointing out the quality and skills of the person sent from social services to help with the care of her father. She is telling an atrocity story about the behaviour of this person – her mother reported that 'he wiped his nose on his sleeve'. This secondary carer was not found to be suitable by this family and there were issues of reliability as the person either didn't turn up or turned up late.

Finding acceptable help was a trial and error experience for the carer in the next extract:

I mean we were having care services every day morning, afternoon and night. Different people to help get in bed out of bed and in the end I thought I can't stand this any more

because there was some young girls in their 20s talking about where they might be going out to which I thought was very unprofessional when their in someone's home and I thought they're not dedicated to their job and didn't have a clue about using the hoist which your meant to be trained up on to a certain extent. I mean I wasn't but I just got the hang of it do you know what I mean? ...So I cancelled them they rang me back and said is there any chance would you want someone in the day sometimes to watch Peter? And there's a couple of women there that are like old school and they do know what they're doing and there the ones that sit with Peter (Wife 10)

This carer describes the behaviour of the care staff, who were young and inexperienced, and lacked skill in using the hoist to move her husband. Furthermore these two carers were talking inappropriately over her husband about their social life. The carer describes how she took action and cancelled this arrangement and now has found two more experienced women carers who 'know what they are doing'. Thus carers can take control and voice their unhappiness with a care arrangement. However this does cause distress for already overworked carers in terms of having to sort out the situation. Care work in this sense is never ending as it requires not only the accessing of help but evaluating the quality and appropriateness of the help provided.

Practical support provided by hospital and social services departments were mentioned by two carers. One reported that they helped make alterations in the house which enabled greater freedom for the patient (Carer 21). Another family had also recently been re-housed to enable the family to have a ground floor house, as her husband was physically disabled (Carer 15).

Support from Hospice and palliative care

Generally many carers reported positive experiences in the support they received from hospice and community palliative care teams. The emotional support provided to the carer was particularly beneficial. However a couple of carers found the link between the hospice and palliative care service and death quite difficult to deal with. In one instance any contact from specialist palliative care was very traumatic as it challenged the family's denial that anything was seriously wrong. The importance of developing a good relationship with palliative care staff was considered important:

And the other person I get lots of support from is the [CNS]. He's very supportive as well, and I've got Elaine from the hospice and I do feel like I have people there if I need them and I know one day I'm going to, but at the moment I'm just coping very well. I

wouldn't want anyone else to look after him at the moment. I want to do it myself. I want to be his carer. (Wife 6)

Later in the interview this carer describes the community palliative care nurse as very nice and someone she can talk to. However for now she wants to care for her husband herself. This carer is satisfied with the palliative care services available. She knows they are there should she need them. They are a service that she may need to draw on in the future.

A number of carers expressed their or their dependent's concern with the link between hospice/palliative care and dying. The carer in the data extract below describes his wife's distress and fear about having contact with professionals from the hospice:

Poppy had almost had an abject fear of cancer and has always kept hospice and people from the palliative care hospice team at,.....didn't want to speak to them. Every time they came near her she broke down in floods of tears (Husband 2)

Unfortunately this carer describes how his wife is frightened of cancer and was very emotional, breaking down crying when the community palliative care team from the hospice visited. Despite this situation the hospice professional continues to visit:

She's visited regularly throughout. But every time she comes, she's a nice girl, very unassuming, Poppy is always heartbroken at the end of it because whether it's because the two of us have lived in denial ever since the diagnosis. It almost hits home when you have someone from a hospice keep coming round (Husband 2)

The carer puts his wife's emotional reaction to hospice services to coming up against their 'denial'. He says that he and his wife have lived in 'denial' since her diagnosis. The link with hospice professionals challenges their denial. It reminds them of the seriousness of his wife's situation and reminds them that she is dying, and this is very upsetting to come to terms with.

A daughter also was worried about the link between Macmillan services and death:

And I suppose having Macmillan nurses involved just means the end.....and that's so hard to take. If they were [specialist hospital] nurses it wouldn't sound so final but Macmillan nurses sounds very final (Daughter 3)

Another carer describes how her husband was initially unsure about taking up hospice day care:

When he first went there he was frightened because he thought oh god why am I coming here – it's cos they think I'm gonna die. It wasn't that at all. It's given him a hell of a lot and me as well. It's been lovely. He's made friends there although some of them have already died over the years so he's had to deal with that himself. But it's an incredible place (Wife 14)

The carer describes how her husband was initially frightened of attending the day care centre in the hospice. However he has found many benefits such as making friends, despite the fact that he also has to deal with their deaths. This service has meant a lot to both the carer and her husband, and had been a very positive experience for them.

A couple of the carers were a little critical of palliative care services:

All they seem to do is ask you what and I think that is their job because Matt hasn't had any pain or anything there hasn't been a problem with pain control or anything like that, which is a wonderful blessing. They said she just phones up and sometimes she comes to see us and like (deep sigh) well she came to see us and she was very good at getting him into hospital when he had these symptoms ...and she got him into hospital into the [SH] very quickly that was all good. But I haven't seen her since, but she does she phones me. She says what medication is he on? How are you? What am I going to say. Oh I'm fine or you're crap so what do you say. Yeah Yeah. I can't even You know I'm just trying to get through a day at a time..and then she says I know it's her job but it's I want something a bit more you know, more than that (Wife 1)

This carer is identifying how helpful the community palliative care nurse is in getting her husband into hospital when he had symptoms. But she would like more support from this person, she needs more than a phone call. Another carer similarly comments on how the palliative care nurse rings up but she would like more practical advice:

We have a Macmillan nurse who just checks up once in a while....she just rings. We haven't seen her for ages actually. It's someone to talk to but again, they don't give you advice so they let you talk to them and they listen but they can't say well you can get hold of this and that... which is fine, but sometimes you need a bit more. I mean you're at home and you think, you know, I want some advice back and they can't give it to you (Wife 15)

This carer describes the community palliative care nurse (CPCN) as someone you can talk to and who will listen. These findings suggest that some CPCNs may not have defined a clear role in supporting carers appropriately with practical problems related to caring for a person with a PMBT and this may be a training need for CPCNs.

There is also evidence from a carer that CPCN may not be up-to-date about what social services are available such as sitters for home carers:

The hospice nurse did not tell me that there is (help available), I did ask her. I did ask her about sitters and I found that there is an organisation but she said 'nothing here there's nothing', but apparently there is an organisation called Prospero, which used to be inroads but now its called Prospero Place carers something or other (Wife 1)

One carer praised the practical support she had received from Marie Curie nurses. This carer's husband is terminally ill and she had excellent support both in the day and at night from the Marie Curie nursing service:

And I've had good support from Marie Curie night nurses. I couldn't have survived without them. They come from 10pm, although you're not allowed them every night, I am really lucky I've been told because I had them four times a week... (Wife 1)

This carer describes herself as lucky to have the Marie Curie nurses four nights a week which have been a tremendous support. It was the Marie Curie night nurse who urged the carer to get help in the day time. Carers need encouragement to access and initiate support services to help them cope.

Other sources of support

A number of carers mentioned the support that was available in their local community, hospital and hospice support groups. The support available from these centres was evaluated highly. Many were praised for providing support for the carer as well as the patient.

The data extract below identifies the range of support available at the local support centre:

The other source of help has been the Apple Tree in Stockley. They are a centre, which support anyone with cancer and they have been absolutely fantastic. He has been going there for a year and a half now. He's had counselling there. He's had treatments like Reiki, massages and a couple of days ago he had a session up there where they were

making necklaces. So it is all really therapeutic stuff and I know he can go there once a week and feel safe. It is a set time say, two hours and that's really great for him (Wife 19)

The carer describes the range of services available at this centre including counselling, art work and complementary therapies such as massage. Furthermore when her husband is there she feels he is in a therapeutic and safe place.

Another carer describes:

...the Cancer Centre who are brilliant. Pat goes there once a week on Thursday...She goes for lunch, they're a lovely bunch of people I'd recommend them to anyone... they have therapies and things, and I can have therapies there if I want them, and I occasionally have a massage when tension brings my shoulders up by my ears....(Husband 21)

In this centre the carer and the patient have access to complementary therapy such as massage and the carer describes how this helps him with tension in his shoulders.

Other forms of community support identified were the carers meeting at the local hospice:

*Well I went to this Carers meeting on Wednesday afternoon, that's down at the Hospice, and they are brilliant they really are. There's no way would I drive down to *** at 4pm-5.30 so you are coming back at 6pm in the rush hour but they will come and pick me up. I don't go every week. They have volunteer drivers. I was there this week but I don't feel I can leave him that long. He can't get himself a cup of tea. He drinks water but our daughter if she is around and she usually is on a Wednesday, she will pop in for an hour or so but she can't stay till 6pm because of the baby. So this Wednesday his brother who only lives at Surrey, he came over and he was quite happy to sit with him until I got back which is 6pm. That was great because they were able to have a good old chat and I think he is prepared to do that again but I don't feel I need this Carers Meeting every week. It's too much of a licence to moan not only me but everybody else. Sometimes you sit there and you think I don't want to hear all this. (Wife 23)*

This carer found the carers meeting really helpful but she was worried about leaving her husband while she attended the meeting. Fortunately family members were able to come and sit with her husband while she attends the group. The group was described as 'a licence to

moan' a way of carers getting things off their chest. She felt it was something she would continue with but not every week. This carer continues:

Well certainly from this Carer's Group I'm able to talk and they are sympathetic and they are very much.....I don't feel guilty when I come away because I feel angry or whatever it is because everybody feels like that so you don't feel guilty that you are talking about them, or disloyal or anything. You are just talking about the way it is.
(Wife 23)

The group allows her to acknowledge how she is feeling in the company of other carers, without feeling disloyal to her husband.

Many mentioned the availability of the specialist hospital's support group which was received positively, but a number commented on the difficulties of getting there in the evenings as patients were tired and some had young families at home to care for:

There is a support group at the [SH] but there was never ever a time since he was diagnosed that he would be well enough to do it. The group at the [SH] is at 7.30pm in the evening. Matt's always too tired by the time he gets there (Wife 1)

Support needs for the future

Many of the carers mentioned their future need for support. Although they felt that they were currently 'coping' they were aware that as their dependent deteriorated they would need a greater amount of support and perhaps, a different type of support:

I'm not looking forward to, inevitably, there will be a time when she's going to deteriorate and the treatment is not going to work. You know, I hope it doesn't but you know I've got to face up to the fact it might. And I'm really not looking forward to that, and if I was to get any help, I'd want it then, you know. (Husband 21)

This carer is acknowledging that he will need more support as his wife's condition deteriorates, when for example she is not responding to treatment or it is not working. He is not looking forward to this time but is aware it is inevitable.

Alternative therapies

Four carers had considered the possibility of alternative therapies (AT) although none of them were currently using them. One carer and her family were considering Tibetan medicine:

We have Tibetan medicine brought from Tibet and from juice from this American friend just the idea nothing in particular. The Tibetan medicine we have just right now in our hands and we would like to try it whenever we finish the radiotherapy and chemotherapy so they wouldn't react but yeah we have (Daughter 4)

Another carer talked about her belief in AT:

I believe in alternative therapy. And so we did meet someone who had a brain tumour some time ago and he sent him a load of stuff about all these different things you can do drink your own urine and that kind of thing. I told him you just have to weed out you know I can see where it's coming from I can see where it's coming from you have to turn the body back strong with you and mend itself. (Wife 12)

Although this carer and her husband had received information about AT they hadn't currently used any therapies. The carer had some belief in the efficacy of these therapies in that she could understand their basis but had not made any decisions to use such therapies. However she had been offered massage therapy for her husband by the hospice nurse.

Another carer describes how she pushed her son to consider AT in terms of modifying his diet but he wasn't interested:

Well originally I pushed Ben [AT] but he didn't want to know and he has the worst diet you can imagine... He eats lots of meat and ready meals, although when he comes to me I cook of course and I give him some greens and he eats lots of chocolate. He doesn't drink and he doesn't smoke, but he eats the wrong kind of things all the time, but he looks good and he's still alive and he's doing quite well... (Mother 11)

In summary, formal and informal support services were present, but sometimes difficult to locate, especially at the beginning of the illness trajectory. Finding a supportive, knowledgeable individual who could give practical help and support was essential to the carers well being. Salander et al (1996) also found that 'a helpful relation' was essential to raise hope for the PMBT patient and the need for such a relation is identified by the carers in this study.

Marie Curie nurses and the practical help that they provided were received very positively by carers. Macmillan and hospice services were generally helpful, although the association between Macmillan Nurses and death was a strong stereotype that some patients and carers

found difficult to overcome. By avoiding their services they were able to prolong their denial that the illness was serious, and for many, this was an important coping strategy. Secondary carers from social services and carer associations had mixed reactions. If they were not considered 'up to scratch' the carers felt unable to rely on them and their usefulness was limited. Similarly, friends and family who understood the strain that the carers were under or who had cared themselves were very helpful. The most effective family support focused on caring for the carer. In some families, the illness had resulted in tensions and rifts, but for most of them, family and friends pulled together. A minority of carers looked into alternative therapies. Carers seemed very aware of what services they could access if they needed additional help in the future. However only one carer had a care manager that had carried out an assessment of her needs.

5: The Caring Role

Although taking on a caring role was not a choice for the majority of carers they all wanted to care for their loved one, and to do the best they could, though at the start they were not sure what the role would involve. Thus they described the status passage in taking on the role of caring for their husband, wife, partner, father, son. This meant changes in role for the majority of carers including role reversal for some of the carers. The carers describe the enormity of the task facing them when they talked about becoming a carer. A number of factors impacted on how carers managed the caring role, for example issues like their dependent's short term memory problems, difficulties with mobility and cognitive and personality changes. Furthermore, many were coming to terms with becoming the sole decision maker, as well as running the household, without the support of their dependent.

Becoming a carer

For all carers, the care giving role was not a job that they had chosen but one that they all wanted to do. It is an all encompassing job involving hard work with no respite as described in the next data extract:

A carer never actually stops. It's a 24 hours a day, 7 days a week, 52 weeks of the year and you're always on the go and even when you do sleep you're still consciously thinking what's going on. As soon as I'm up I think...and I don't sleep in a deep sleep.. the slightest noise and I wake up... (Wife 15)

This carer describes the unrelenting care work she is involved in. It is always on her mind, interferes with sleep and it is non-stop. Unlike work outside of the home you can't get away from care giving work and it never goes away.

Becoming a caregiver is not easy and one man referred to how caring is natural to some people whether they are male or female. However, he was also feeling that he needed to be armed with more factual information to do his job well. It is a job that is thrust upon you with no specification of how to do it well:

Obviously if it's in your nature to get on with it and try you will. But say the pitfalls I see for carers is that they need the medical information... I mean there should be some

form of checklist – is the carer male or female, because just because she's female she may not be able to cook.... Nobody at any time when the (patient) is released... no-one checks that you are capable of dealing with them when you go home. They don't know that I've got a wife (with Parkinson's) as well.... (Father 5)

This father describes care work as complex, with pitfalls. One of these pitfalls is a lack of medical information. He suggests that a checklist of the skills and knowledge needed to give adequate care would be helpful. Also gender may impact the caring situation but there is no guarantee that the carer, whatever their sex, is able to carry out the role adequately. He identifies one of the skills as preparing meals. The other point he makes is that no one assesses the capability of the carer in relation to their ability to give care. This carer also has two major caring tasks on his hands. His son has a PMBT and his wife has Parkinson's Disease. Having two people dependent on him makes the caring role even more challenging.

Another carer mentioned feeling guilty about leaving her husband or relinquishing her caring role to another person:

and another thing I've felt is guilt. I feel guilty like sometimes you have care watch from an agency and they'll sit with Alan or help him go to the toilet and all that and they give me a few hours to get out and about, but I feel guilty, guilty at leaving him stuck indoors dwelling on things. So I don't really enjoy myself if I do go out do you know what I mean? (Wife 10)

This carer felt really guilty leaving her husband in the house with a paid carer, while she was out, which meant she really didn't enjoy herself because she was thinking about him 'dwelling on things' in the house without her. Therefore even though secondary caring services are available it can be difficult for carers to use them because they feel a sense of guilt in having time out or letting someone else give care.

Another carer spoke of how she and her husband were still in denial about the seriousness of her husband's condition and this helps them remain hopeful:

I do have hope regardless yes I do. We are still in denial in a way I think that's going to be like that for a long time me and my husband and we still think gosh I can't believe this is happening would you believe it. You know just and I think this is normal people

with cancer I heard that before. So we do have hope because if you don't have that we would just sit down and wait and see what happened. (Wife 17)

This carer recognises that she and her husband are in 'denial' of their situation. This carer in particular is spending a great deal of time looking for second opinions and other treatment options for her seriously ill husband. She recognises that her reaction of 'denial' is 'normal' for people who have cancer and she understands this but this means she can retain hope and remain active searching for information to help her husband survive. Other carers spoke about major changes in role since their dependent became ill. This is discussed next.

Role change

In the following data extract a carer speaks about how husband and wife roles have drastically changed:

It's a completely role reversal. He doesn't say it now but for a long time, I'm not being nasty about him, I'm not saying he's controlling inasmuch as he has to insist on everything, I don't mean that but if he wanted to do something he'd do it but similarly I was free to do things. You can tell he's got over it now I think but for a long time I would say to him come on get up now, or whatever it was, and he'd say yes boss and I hated that. For him that's how it felt. (Wife 23)

This carer refers to the traditional roles of husband and wife and how their roles are now completely changed. She suggests that her husband was more dominant or 'controlling' and she now has to tell him what to do such as 'come on get up now', which her husband resented when he replied, 'yes boss'. This role reversal is stressful for both the husband and wife but she appears to try and take his perspective when she says 'For him that's how it felt'.

Another young wife refers to how she has had to change in relation to her husband's illness:

In one respect because you know we are a young couple and um, previously he was quite a protective kind of character and now I feel I've almost got to protect him, you know, in a sense um. You know I go to work and support the family, um, you know and its not nice to see your husband upset and in tears so I sort of try and be as strong for him as possible. Some days we both sit and, well we don't tend to do it so much now, but when we first... well we cried but we haven't and we've had lots of giggles but we used to sit there and hold each other and cry and just..... I think its almost like you have

to go through, and this is what I feel like, like I've gone through a bereavement and I've gone through all the stages of anger and denial and guilt. There was like, oh why didn't I know he was getting this, especially when you're a nurse, and I think I've gone through all those and I think I've come to that final state, I think it's acceptance in bereavement isn't it? I feel because he's had it six years this year, it's a long time and you have to.... you can't keep crying. You can't keep getting angry and saying why us because that's not going to do Tom, me or Emily any good at all. (Wife 19)

This carer now wants to protect her husband when in the past he was the protective character who rarely showed his emotions. The carer reports how her husband is much more emotional than before his illness started. They both share their emotions with each other by crying together but now she is trying to be the strong one. This carer also describes how she has gone through a period of loss and bereavement and has come to a level of acceptance of the situation over a period of six years. This couple have had many years to come to terms with their situation in contrast to other families.

Dealing with Short Term Memory

Every carer alluded to the problems of coping with their dependents short term memory loss. Many people could remember events from the past in great detail, but struggled to remember recent events. This impacted the carer in a number of ways including affecting their relationship, causing feelings of isolation, mourning the person that they had lost, and requiring copious amounts of patience as many reported having to constantly repeat themselves.

In the next data extract the carer refers to the limitless patience she needs when her husband asks her the same question over and over again:

When I come in from work if he asks me once, he asks me a dozen times what we're having for dinner tonight and that's the main problem and that's why I don't want him to go out on his own in case he forgets where he lives or something because his short term memory is bad. But I've got used to that now. To start with I found it very upsetting to keep being asked the same question over and over again, but it's three years now and I've just got used to it. (Wife 6)

This carer is worried about her husband's safety should he go out and gets lost when he forgets where he lives. She found dealing with the loss of memory very upsetting and it has taken her

some years to get to used to it. The short term memory loss is a major worry for this carer. However later on in the interview the carer describes how she now copes with her husband's loss of short term memory:

... but I've got to the stage now, if he asks me once, and then next time he asks me the same question I treat it like a different questions and I answer it as if it's the first time he's asked me... (Wife 6)

This carer had a technique of treating the repeated question as if it was being asked for the first time. This technique enabled the carer to feel less frustrated, and enabled her to handle the situation in a calm manner through re-taking the repeated question, as if it was the first time it was asked.

Others used humour to alleviate their frustration:

Sometimes (the short term memory) drives me to insanity. Sometimes we laugh about it...it has got progressively worse... We had a good giggle about it the other day.... We were driving somewhere and I had said something to him 5 or 6 times that morning and he asked me again, and I just thought I feel like super mum, 'you're driving me mad', but I think that's the only way you can cope (Wife 19)

This carer identifies how loss of short term memory is something that gets progressively worse. However, the couple are able to have a sense of humour about it and she uses the term 'we' which demonstrates that they together cope with this problem through having a 'good giggle' and with the carer being open about it in her expression 'you're driving me mad'. This is how this couple cope with the situation, they acknowledge it, and laugh about it together.

Another carer describes how she had to tell her son what to do when he couldn't initiate what to do next:

At Christmas time we were unpacking some presents from the boot and Ben stood there for an hour outside by the car.... If he has a day like that there's not much you can do... you have to say 'Ben, sit down, and then he says, 'yes' and he does it. (Mother 11)

In this situation Ben seemed frozen in time or vacant, just standing doing nothing outside by the car. On the days when her son is like this there is not a lot she can do other than tell him what to do next and he obeys her command to 'sit down'.

Some coped by concentrating on the past, and focussed on the long term memory capabilities, which seemed to be unaffected by the brain tumour:

He's the same person. We talk a lot about when we first met as he remembers that. We met through a church youth club. We were fourteen and we talk about that (Wife 6)

This carer emphasises that her husband, despite his loss of short term memory, is the 'same person'. His long term memory is intact. So as a couple they talk about when they first met at fourteen at the local church youth club. Therefore this carer draws on her husband's capabilities in relation to his long term memory to overcome the problems of his short term memory and this enables her to see him as 'the same person' she met all those years ago and married.

Another carer describes how her father writes things down as an aide memoir to trigger his memory:

It's day by day – had this for breakfast, had this for lunch, went to bed at such and such a time, went out in the garden, pruned the roses whatever. He would write that down and he would probably mostly be very good but he wouldn't, if you asked him what he did yesterday, he wouldn't be able to tell you. Did you go out in the garden yesterday? Did you have a walk? (Daughter 3)

Writing things down was one way her father could remind himself of what he had been doing on a daily basis, which is a helpful strategy. However answering spontaneous questions from his daughter about what he was doing yesterday was now beyond her father. Another carer adopted association strategies to help with the short term memory problem:

You go through the food options and in the end you would make something, 'sure that's what you want?' 'Yes'. You'd go out there and cook it and he'd say 'I didn't ask for that did I?' and you'd say 'yes you did'. Now I've discovered that the best thing... is if I say to him 'you said you wanted that' he would look at me and say 'I don't remember that'. But if I say 'you were cleaning your shoes', you were doing this when I asked and you associate it with something else he either remembers it or he thinks crikey it must be right..... at least I then got him to eat because he wouldn't eat before that. (Father 5)

This father was finding it very difficult with his son changing his mind about what food he wanted to eat. The strategy adopted by this father of linking and associating the decision about

what food his son asked for, with the activity his son was involved in at the time appeared to work well. This was a technique that this father worked out for himself and was pleased with the result as his son was now eating the food he prepared

Changeable moods and personality changes

Personality changes and changeable moods associated with a brain tumour were mentioned by all the carers. Moods changed over time as the illness progressed, and carers had to adapt to the physical changes as the inevitable psychosocial and emotional changes in the person they are caring for. One carer describes the complete change that a brain tumour brings:

Brain tumours change you completely. They change your personality, you have good days and it's a long time to be ill (Wife 19)

This carer suggests that nothing remains the same as the brain tumour causes a complete change in personality. There can be good days and this is over some time as her husband has survived now for six years.

Another carer describes how her husband became much calmer and more serious following his diagnosis:

He's had always been a builder so he's always laughed and sworn and that and he got very correct with his speech and didn't like swearing and anything like that. We sort of rowed our way through thirty happy years and suddenly he was much calmer. I should have been happy but it wasn't my husband really. Then three weeks into the radiotherapy I could see that it was working because I got him back. (Wife 1)

This carer again describes the complete change in her husband from someone who laughed and swore to someone who is now very correct in his speech. As she points this change meant 'it wasn't my husband really'. However after three weeks of radiotherapy he was returning to his old self as she describes how 'I got him back'. The changes in personality and mood are what make caring for a loved one with a brain tumour so difficult.

Another carer describes how his son is now very 'laid back':

He's always rushed around..... since then (the tumour) all this rushing around has stopped and he's been so laid back it's unbelievable. I don't know if it's nature dealing with it or what (Father 5)

This father contrasts his busy son who rushed around a lot becoming much more calm and he see this as positive. So changes in behaviour and mood were not necessarily seen as negative and not necessarily linked with the physical changes associated with the brain tumour as this father links it with 'nature dealing with it'. This is interesting because this father suggests that the changes occurring may be a natural adaptation to the situation not necessarily a biological change.

This carer describes changes in his wife's personality and links it with steroids:

I read one day the side effects of dexamethasone, which is the steroid she has been on for the last year. I think it was twenty two symptoms and she has I think eighteen of them; including inability to cope with stress, mood swings, so yes she has all of the above and as you saw just then I checked in to see if she's alright and she says 'that's enough now'. (Husband 2)

This carer is knowledgeable about the side effects of steroids on his wife's mood and emotion. Klein et al (2001) discuss how steroids and anticonvulsants produce further adverse effects on cognitive function.

He continues to discuss how frustrating he finds his wife's behaviour particularly when she is reluctant to communicate with friends:

Well I've said to her at times, in the early hours of the morning or if we are out busy doing something, or if we are trying to do something, she will.....well I have to almost shout at her that there are other people in the world that everyone is trying to help her and that when friends ring up to see ask how she is and she says I don't want to speak to anyone now, that's not the way to repay people's concerns. (Husband 2)

This carer is finding it difficult to cope with his wife's behaviour as he describes how he has to 'almost shout at her'. His wife is self absorbed and wishes to withdraw from social contacts with friends. There is a profound change in their social situation with his wife refusing to communicate with friends that this carer is finding difficult to cope with. The carer describes later how: '*there's only glimpses of the person that I married*'. He continues '*I've lost it a few times over it, you know, had a mini breakdown, broken down in tears*'. The situation that this carer is describing is profoundly upsetting for him as the change in his wife is so marked.

Another carer refers to how the sexual side of her relationship with her husband has changed:

We don't sleep together no more because he can't get an erection cause it has changed really because I'm his carer now more than anything I mean I still love him dearly. You know that's never changed I wish we were back to normal but I don't know it does feel that I've lost him part of him how he used to be you know. He's different in a way I'm mourning the loss of part of my husband even though he's still here. In another way when I talk to him about it especially if I talk to him on the phone when I'm not here which is very rarely it doesn't feel like he's different at all you know what I mean
(Wife 10)

This carer describes how she is mourning the loss of her husband and the loss of their sexual relationship. Another carer (14) also described problems with sexual relations due to her husband's changed personality. This carer (10) is mourning the many profound changes in him as a person. Her husband is described as 'different' but when she talks to him on the phone she gets a glimpse of the person he was, as his physical body is completely changed.

Carers were coping with profound changes in relation to their loved one's personality and behaviour. However, these changes were not necessarily seen as negative as carers were able to use a number of strategies together with their dependent to overcome the changes they were experiencing. Strategies such as humour, association techniques, making more use of long term memory, reframing the carer's mind set to deal with repeated questions and re-taking them as if for the first time were frequently used. However some of the changes experienced were very difficult to cope with, such as a previously outgoing and lively husband becoming more serious and a wife who has withdrawn from social contacts with friends and profound changes in intimate relationships and sexuality that carers did not know how to seek help with or whether help and advice was available.

Safety and Mobility

PMBT is known to cause unsteadiness and weakness in 42% and 36% of people respectively at hospital presentation (Grant 2004). Problems related to mobility had an impact on the intensity of the physical role of giving care. Partners and spouses were often giving physical help to their dependent such as help with washing and dressing and supervising all aspects of physical care. Safety was also an issue in relation to falls within the house when showering and going to the toilet.

As mobility lessened, the carers often found themselves being relied upon even more:

Since she was operated on initially and her right hand side started to go and her writing was going and her speech was going, and um, obviously they operated and removed as much of the tumour as they can, put her on a course of radiotherapy. After that the use of her arm came back and her speech came back but she still had this drop foot to contend with.... Then that lasted a good few years and then her side started to go again and it meant that I had to do an awful lot more... I had to dress her, get her out of the shower, out of bed, go to the loo, all of those things she needs help with. (Husband 21)

This carer reports how much help he is now giving his partner related to dressing, washing, toileting. This is hard physical work for the carer. He is also worried about her falling:

she's very unsteady and its always a constant worry that she'll fall, and she does, and I can't get her up on my own, and that can be a bit of a problem....(Husband 21)

Another carer reports the sudden deterioration in her husband's mobility:

Basically he's got a tumour in the right side of his brain so its affecting the paralysis on the left side so his arm and his leg. He does, hence we've got the bed down here now. But at Easter he was fine and in the week after it all just started to kick in..And then all of a sudden, he wasn't so it's had to be taken on fairly quickly...but obviously taking him to the loo, and wheeling him round in the wheelchair and getting his clothes out and things like that. He is able to wash but not get in the bath and things like that so....He is quite a determined person so wants to do a lot for himself. We just have to be a bit careful he doesn't do too much, you know. (Wife 22)

This carer describes how her husband's left side is affected and how quickly his mobility has deteriorated. She is now helping him with all activities of daily living although he is still able to wash. Also her husband wants to remain as independent as possible at this stage. She goes on to describe how quickly her husband's condition had changed:

Well it has really yeah, because the first session of radiotherapy he walked into the hospital, dragging his leg a little bit. That was on the Friday and on the Monday I had to get a wheelchair to take him into radiotherapy and then he was kept in because he got very weak over the weekend and that's when he came out of hospital not being able to walk at all. He can move himself from chair to bed and wheelchair to armchair, that

type of thing but he's got to be.....he can't really walk, and so it was just very rapid, you know, and er, in a week you had to adjust your whole life really and the house, you know. (Wife 22)

This carer is describing the dramatic changes in her caring role as her husband's condition deteriorates very quickly. She needs to make changes to the house such as bringing her husband's bed downstairs. The changes affect everything and are difficult for this carer because of the speed of her husband's deterioration.

Another carer describes how her husband was very active, keen on sport and is now confined to a wheelchair:

Because he's such a sportsman it's hit him so hard. He's got a grade four tumour which has affected his mobility which is for him the worst thing that could have been affected. He's left handed and it's his left side which is affected.... So he is unable to write....It's his walking too. He was on a stick, he had pneumonia in November went into hospital for a week and when he came out they sent him out with two walking frames, wheelchair and that's how he is now. We've had to buy a stair lift because he just couldn't do the stairs and now he's reduced to a wheelchair when he goes out, but he hardly goes out. When he goes out he wants to sit in the wheelchair all the time. (Wife 23)

This carer describes how her husband has been hit very hard by his problems with mobility. Like carer 22 they have had to make extensive changes to the house with a stair lift installed and using a wheel chair to go out. The carer goes on to describe how her husband has 'fallen twice indoors' because he is 'over 16 stone now' due to 'the steroids'. She had to call the ambulance to help him get up following his fall. Clearly carers need help in preventing and dealing with falls.

Tiredness

Every carer interviewed mentioned tiredness as a major factor that interacted with all the other issues related to having a brain tumour and caring for someone with a brain tumour. For some, the frustration of caring for someone who suffered from constant tiredness and apathy was difficult to come to terms with:

(as a carer) you get frustrated with the fatigue and things, 'why doesn't he do this?' and 'why doesn't he have a shower?'.. and my friends and my sister said' you know he can't do it' and it took a long while for me to understand and to be patient, and that has been hard. When I a shower I take two minutes. He takes an hour And I feel he's going into another world. I say, Ben, come on, wash, take the soap... it's almost like being a baby (Mother 11)

This carer found it hard to come to terms with her son's fatigue and the length of time it now takes him to do things like taking a shower. Again for this mother it is almost like going back to babyhood with her son, as she has to keep reminding him to get on with his wash. She describes how it took her a long while to learn patience. This situation describes the mutuality in the caring situation in that carers have to develop new skills and attributes like patience in order to do their caring work well. They also need help, like in this situation from friends and family, to understand the profound change in their dependent when she was reminded that 'he can't do it'.

Others had a greater understanding of the impact of cancer treatment and the tiredness that this can bring, and tried to encourage their dependent to accept it and work with it rather than fight it:

I think it helps because I am a nurse. I do have some kind of understanding and For example, last week he was really tired and he sat here and he said ' I can't go on' and you know I said,' you're tired, you've got a brain tumour and you're going through chemo at the moment which is going to make you incredibly tired' So I said ' if we go to Crawley.... You go and have a cup of coffee and I'll just walk around the shops' and he's really happy to do that and he said ' yes, that's a good idea' (Wife 19)

This carer describes the profound level of tiredness that her husband was experiencing when having chemotherapy in that he was voicing his inability to go on. Her training as a nurse allows her to understand this side effect of chemotherapy and she was able to point this out to her husband making the link between tiredness and chemotherapy in a way that helped him to go on.

For this carer his tiredness was linked with steroid therapy:

He's tired, very tired. It's the same with this infection he's just had, it's left him so weak. This last few days really.....he's still on steroids as part of his treatment which the hospital doctor, consultant wants to bring right down and he's down the lowest he's ever been but it takes his energy away. Our hospice nurse feels he should be on a slightly higher dose as maintenance...Apparently [steroids] makes your muscles weak, which is the problem. The effects of the chemo, his tiredness, and lack of mobility and that's his main symptom anyway so its all exacerbating the symptom if you like.. (Wife 23)

This carer is aware of the side effects of steroids and their link with muscle weakness. However she also links the low dose of steroids with taking his energy away. The hospice nurse is advising a slightly higher dose of steroid to combat the symptom.

Patient's Attitude

Many mentioned that the attitude of the person they were caring for was a key aspect in the caring experience. A positive and optimistic outlook in the face of such a challenging illness made the role of caring significantly easier to deal with.

The father in the data extract below describes how his son is cheerful despite his serious medical condition and potentially poor prognosis:

They said to him at his last visit to the [specialist hospital], they said 'how are you getting on?', and he said 'oh alright', and he's quite cheerful. And it's interesting that you see they only engage with Karl and about three others I've seen to the same level. And I think it's, we are all human beings, but a lot of them, what shall we say, they are suffering this but their glass is half empty and Karl's glass is half full. He knows he's probably got eighteen months but he says 'I'm going to live till I'm fifty but I'm only thirty something now and that's been his attitude, which is great (Father 5)

This carer describes his son's optimistic attitude as great despite the reality of his long term prognosis, which the father and presumably his son is aware of. Karl is perhaps coping with his condition by an attitude of optimism and this also helps his father who admires his spirit.

Another carer describes how her husband has outlived the prognosis of one year that he was given and he is a pessimist:

Of course he's gone past the year and during that time you see he has said, I've had to be very careful really what I say, but he's said when we got to August, one particular day he noticed the date on the newspaper and() because it was over us and it's strange now when we got to January and we went past it and he didn't seem particularly pleased.....because he is a pessimist I must say and a friend said to me perhaps he feels that now he's on borrowed time. He won't talk about it. He won't talk about that side of it. He won't talk about dying or afterwards or anything but then he's always been that way. (Wife 23)

This carer's husband is described as a pessimist and reluctant to talk about his situation. However the carer reports that her husband is aware he has survived beyond the one year prognosis he was given. Although the carer noted that he doesn't seem pleased about this. Also he is reluctant to talk about his situation and the fact that he is dying with his wife. However the carer reports that he has never talked about these difficult subjects. Fortunately this carer has support from her friend who is caring for a chronically ill wife and she also goes to the carers support group, where she can off load some of her worries.

In summary, the caring role was mitigated by a plethora of psychological and physical problems such as poor short term memory, mobility problems, tiredness, and personality changes. What was most challenging is that these issues often had a fast onset and were constantly changing and developing as the illness progressed, so carer's and patients needs differed from one month to the next. Personality changes seemed to be the most difficult to deal with and the carers spoke of a profound sense of loss and mourning related to these changes. Carers employed a wide range of coping strategies when dealing with short term memory loss such as humour, cognitive re-framing, and using the past, where memory was less affected to re-establish their relationship. The patient's attitude had an impact on the caring role. Patients who, against the odds, managed to remain cheerful made the caring role easier for their loved ones. Carers who were not able to talk with their partners found other sources of support outside of the family circle.

6: Surviving and managing

Many carers not only had the problems of managing their caring role but also had to keep the household going, such as paying the bills and going out to work. The illness of their dependent meant in real terms often a fall in the household income. There were significant financial implications, especially when the person with the PMBT was the major breadwinner and had dependent children. The impact of taking on a caring role will be discussed from a financial, emotional and practical perspective.

Carer's Employment

For those that continued working, a new set of problems emerged. They needed to arrange cover so that their dependent was not left on their own while they were at work. Often friends, neighbours and family members helped out as best they could. In the next data extract this carer managed to get to work with the help of friends who came and saw her husband off in the ambulance:

So what happens, I get him ready in the mornings and then friends come round about quarter to nine, when I have to go to work, and they stay with him until the ambulance picks him up. He goes off to the [SH] and then I mean it's only started to happen this week but a friend came back and saw him in the house until I got back home. You know we've got a good circle of friends fortunately... we belong to a local church so there's a good few people there that ...and my son's doing a degree at the moment so he's a bit free-er. He might be around in the day but once he starts work, laughs, he's not going to be doing that. (Wife 22)

This carer is managing to work with the help of people who belong to their local church. This carer had a lot of practical help from her church, which was an unusual situation as most carers relied on family members and very close friends.

Another carer reports how both she and her husband were self employed. The carer was a childminder and although she has had to severely restrict her work with young children, due to the demands of caring, the mothers of the children she minded have been extremely supportive to her:

I'm lucky because I've been a childminder for so long some of my mums have become good friends you know and now they know you have they say we will be here for you, you know when you want us we can I'm lucky like that. There are the ones that I've been there for them with their children I suppose. So you know I've helped them out with all sorts of things and I'm lucky like that (Wife 1)

This carer is describing a reciprocal helping relationship with the mothers of the children she has minded in the past. They are now helping her as she once helped them.

For many, the impossibility of trying to juggle work and caring eventually became too much and they were forced to give up their job prospect and take a less demanding role or give up work altogether. This male carer found his work and promotion prospects affected by having to care for his wife:

It is, and unfortunately I had just got a promotion three weeks before Mary was diagnosed and work has been difficult because obviously when you go to your bosses and explain the news they immediately say, as everyone does' take as much time as you need'. And then when it runs into three to four weeks and you are in maybe one day a week and then you start realising that the Company only gives five days compassionate leave per year and then it starts to affect things when it goes into seven, eight, nine, ten, eleven months and its very difficult... They suggested I do something else, look after a quieter system, and I didn't want to be seen to have failed but nevertheless the pressure was too much and eventually they gave me the big hook – you know – go off and do this, done enough, we need toand I was sort of scapegoated slightly. What I said to them at the time all along was that what I need is stability. It might be busy, it might be hectic but it means I don't have to think, I don't have to learn anything new it's just what I am doing and I can drop in and out (Husband 2)

Others found it impossible to maintain their career as they no longer had the time to dedicate to it:

I've always survived on word of mouth and when I was up in town that works... but when you're down here you're lucky if people remember who you are.... Or what you do...I have a website which I haven't had a chance to update it... I'm so time limited, that's the big thing. Even if I had lots of work I wouldn't have time to do it. I tend to work at night, and ... you know, try and sort things out on the computer and do web based things, and I don't go to bed till 2am, then I get up at 8am....(Husband 21)

This carer has become a self-employed graphic artist but he is time limited due to his caring commitment, which means he has to work at night and make do with less sleep.

The change in social status that occurs when both partners can't work was described by carer 10 as 'beggars can't be choosers'. They had been given notice to quit their house by their landlord and were now seeking to rent a house for themselves and their two young children. Prior to her husband's illness they both had been in the police force. Although both husband and wife were still receiving full pay they were aware that this could not continue indefinitely. The police force had been very supportive to this couple. They had regular visits from colleagues and the chief constable had also visited. This was perceived as extremely supportive by the couple.

Finances

Finances were a great concern for many carers, most particularly in cases where the dependent had survived for some time. One carer, had started borrowing against the equity of the house, although this was not a long term solution to the families financial problems:

At the moment I'm living on the equity in the house, and it's come to the point where I can't do that anymore or I won't be able to buy another house... so this year I've got to seriously sell it, last year we were going to do it, but it sort of, the thought of moving is so horrific....Well it's a lovely family house, and the children have all grown up here, well they're still growing up here...(Husband 21)

This carer was in the situation of having to sell his house to free up some money for them to continue to be solvent. The thought of moving is 'horrific' but financially this is the only way he can survive.

Another carer describes how his son is on half pay but there are some problems with his son's ex-wife:

He's still on half pay next pay day but I try to get him to go to Citizens Advice because he's still having to pay his ex-wife but she's already told him that she's not taking any cut so she's expecting (Father 5)

This father reports problems with his son having to pay his ex-wife when he is going on to half pay. The father has suggested seeking advice about this from the Citizens Advice Bureau. The son's ex-wife is described as putting pressure on his son for keeping up the current level of financial support to her and her young family.

Another carer described how her financial situation had worsened over the years despite her working at a full-time job. They had their mortgage on interest rate only:

But at the same time I don't know how long he's going to live for soit's a difficult one. We always say that the longer he survives, the worse off we are going to become financially. And that's terrible. That is unfair.....and we do have an insurance policy that we took out years ago, it'd ridiculous because it's not even a lot of money but if anything was to happen to him before the year 2012 I'd get a lump sum of £50000 and that was because we wanted to make sure at the time that Sarah was settled, our youngest, if she'd been to University or what have you and anything else but the horrible thing about it is that if anything was to happen to him after that date I won't get anythingwe stopped paying his pension years agoapart from anything else you've got the worry of all the finances as well, it's quite a struggle (Wife 14)

This carer had a husband who is surviving over many years, but he is currently unable to work. He is not contributing to a pension and she was on a low salary but in full time work. Their insurance premium would only pay out if her husband died before 2012 and there was a lot of uncertainty around his prognosis. She is unsure of how long he will live. Their situation is described as horrible and unfair.

Claiming Benefits

Unless someone championed their cause, many found it difficult to find out what benefits they were entitled to particularly when there were other dependents such as young children:

they only inform you about the basic ones. They don't actually say to you if he's got this he can get this and that. Really you need someone to go into an office and say right, I've got a terminally ill husband, this and this and this is going on, this and this it's been long term, and they should be able to come back and say, right, OK he's had this for so long so you should be entitled to this benefit and you might have to go on to this one for yourself etc. they don't tell you.... When Charlie did go back to work, we did it

all properly. But because he was on dual benefits, which was incapacity and income support, they don't tell you that you can only work on income support up to sixteen hours but on incapacity you can only up to fifteen. He was working sixteen hours. So you're doing what they tell you and then a year later they say you owe them all this money back because you've worked sixteen hours... but they never tell you that at the beginning. (Wife 15)

This carer describes some confusion related to the benefits they were due and income support. So when her husband went back to work part time they didn't realise that their entitlement would change.

For those who received support, and whose cause was championed by a knowledgeable individual, the story was very different:

The social services man at the [Specialist Hospital] he's going to arrange for John to have incapacity benefit as John's only sixty one, as he's entitled to it till he's sixty five. We also get disability living allowance which Tim also organised, we didn't even know we'd be entitled to it. We also got the motability bit, and he said you're entitled to it, you've worked since you were fifteen. I've got a pension, John's got a pension from the post office and I get my state pension now so financially we're fine. (Wife 6)

This couple were very happy with the information they received from the specialist advisor at the specialist hospital. Specialist advice like that available in the specialist hospital is essential for patients and carers. Carer 15 described how she had not been aware of her entitlements and had not received adequate information about benefits when her husband first became ill.

Another carer received good support from a social worker:

Our GP linked us up with this social worker, and she was brilliant.... He's on incapacity benefit and she helped us fill out the forms for him to get lower rate disability benefit, and then when he deteriorated she said you're entitled to the disability badge... (Wife 19)

Claiming benefits was complex process and it could be difficult to find out what you were entitled to. One carer was very unhappy with the financial situation and she needed help from her parents in paying her mortgage:

I made hundreds of phone calls to find out that in actual fact we are not really entitled to anything because he's getting statutory sick pay and its over and above what the government say you need to earn a week, with the DLA, Carers allowance, and his statutory sick pay was more that £160 per week therefore we are not entitled to income support. So I'm very lucky that my parents are paying my mortgage. That's what it's come down to - my Mum has been buying food and all sorts of things like that and my Dad's been paying what's left that we can't afford to pay. (Female partner 8)

This carer was finding the financial implications of her partner's illness very difficult to deal with. She found that her and her young family were entitled to very few benefits and her parents were helping her out by paying the mortgage and helping with buying food.

Support from utilities companies

It was also difficult to find out about other forms of financial support. One carer mentioned that utilities companies will reduce your bill if you were a full time carer as outlined below:

I found out this week, we'd kicked up because we had an EDF (electricity) bill for £300 and I found out when I called that they do a carers line which I am now on but also you can get a discount off your bill if you've got a terminally ill person at home, which nobody tells you about. They can't take it off the bill I've already got but they can do the bills in the future, and also if you have a large bill the Company have a number you can ring and actually get help to pay some of the bill which I didn't know about either..." (Wife 15)

Some carers like the carer above had become very expert in relation to what financial support and benefits she could access. This carer had very little help until she found a good contact within her local carers group who could advise her on which benefits she was entitled to. Since this time she has become expert on the benefits system.

Impact on Carer's Health

Many carers felt that their health had suffered as a result of their caring role. Carers described a range of conditions that they suffered from such as depression:

I was on antidepressants.. They thought I needed them but they slowed me down so much I mean I had a thousand thoughts going through my head but I was much more

dulled down than I want... I can't remember to take the antidepressants and I didn't think they were doing me much good anyway... (Wife 1)

Another mentioned trying to avoid getting depressed as she is fearful of being prescribed antidepressants: 'I don't want to go down that road of getting depressed and going on antidepressants and stuff like that at the moment'. (Wife 10)

Another carer describes how her asthma is exacerbated because of all the stress she is under:

I'm asthmatic and the stress of all this has bought it all on again. I mean I'm on medication but I'm coping.... But it was because of me not being very well two weeks ago that he said 'I don't want you to go to work for the last 2 months', so he persuaded me to cut down from 4 days per week to 2 days. (Wife 6)

Another female carer has lost lots of weight and the GP commented on this: '*and when Charlie went to the GP yesterday she came out and said I was too thin again*' (Wife 15). carer put her weight loss down to all the running around she does.

One carer was caring for his mother with Alzheimers and his father with a PMBT. He was suffering from high blood pressure and was worried about his relationship with his wife and the impact the caring role was having on it. Caring for more than one person seems to make being a sole carer extremely difficult if not untenable, and has health and relationship consequences for the carer:

I'm going to end up with a divorce I think because I'm there all the time and it's putting pressure on my marriage and work as well, because I'm frightened of getting the sack. You know all that worry as well. (Son 16)

This carer had many worries, his health, his job and his relationship with his wife. He was in a difficult situation of having both his mother and father with chronic health problems that caused him a lot of stress. Furthermore there were difficulties with his siblings about the best way to care for his parents. At the moment they were both in a nursing home.

Impact on children

Family life also suffered, especially for those carers who were also trying to look after young children. One carer talked about ‘juggling’ the different demands of her children and her husband:

We find it very difficult juggling for example getting them up for school in the morning and then Charlie needs helping to dress and then I try to get out for some part of the day, not.... Because obviously we can't but for some part... it's juggling everything alongside in between you've got Charlie needing stuff and wanting stuff done, me trying to get me own down, and there's ironing and washing and you've got four children so how do you have any spare time? That sort of thing, do you know what I mean, and then it's bed time. I'm lucky to be in bed by eleven or twelve, and then I'm up at six am. (Wife 15)

This carer describes the hard physical and psychological work of caring and then the reduced time she has to recoup and sleep.

The psychological impact on the children of knowing that mummy or daddy was very sick was also very difficult to deal with:

I felt our young daughter was fine because ever since she has known her daddy, since she was three,.... He has always been at home... and we say he's got this bad thing in his head, but, over Christmas she was beginning to show a lot of anxieties and I sat down with her and I realised she had a lot of issues to do with her dad which she had obviously brought in so they had a children's counselling group once a month so she attends that and has linked up with this other family whose dad has also got a brain tumour... (Wife 19)

The carer described how her daughter had become disturbed by her father's ill health and had become ‘neurotic’ about her health. The carer said that she often had phone calls to pick the child up from school when she wasn't very well. Fortunately this child was referred for counselling at the local cancer centre.

Some hospices offered support directly to the children, and for one of the male carers this was extremely helpful for his teenage son:

[The hospice] have a care worker called () has started calling our sixteen year old son on a regular basis. I've never met the lady although she did once come to the house to meet my son and unfortunately I was just going out (Husband 2)

Furthermore, keeping up with the everyday practical issues of family life such as shopping for food with a family member in a wheelchair presented more challenges. One carer mentioned that supermarkets will sometimes help you if you go on a certain day, as outlined below:

It's the simplest thing and yet if you try going shopping for six in the week when the children are at school which would be easier but you take a wheelchair, those silly little trolleys that go on the front of the wheelchair don't do a family of six. Tesco in Horsham are pretty good. If we go on a Tuesday they will get someone to come and push the trolley for us because it's their quiet day. (Wife 15)

Preparing children for the inevitable death of their parent was an emotional rite of passage. This carer approached it by talking openly about the inevitability of death and tried to find ways of signifying the event that was going to happen at some point in the future. Buying lockets for each of his daughters was his way of saying goodbye.

On Saturday we took the girls out and Charlie chose two different lockets for them each and then we let the girls choose and we were explaining that Daddy will die and he wants a locket to leave in a box for the girls because we are going to do special boxes and in that box, what locket would you like? Daddy likes these two but he wants you to pick the one you would like. Niamh just said it's alright Daddy I like that one but you're not going to die just yet are you? We say 'no not yet' but the time will come. And we feel that by talking openly to them as it goes along it's not going to be such a shock when it happens as hard as it will be. I feel that also if a child grows up and it's a normal thing to hear for them, it's normal, they know it's going to happen..... Chloe doesn't talk about it, she doesn't want to know... if you mention it she puts her hand up, stop, and you know, ok we'll steer away from it. But on Saturday she was going... I don't want you to leave me yet Daddy and he was saying no, I'm not going to leave you yet but I like that one. (Wife 15)

This carer describes how difficult it is talking to young children and preparing young children for their father's death. This couple want to be open with their girls about what is happening and to talk about the fact that their daddy is dying. The couple together are tackling how to

prepare their children as they use 'we' to refer to 'special boxes' that they are preparing for the children and in which they will put the lockets. This carer is talking about making talk of death a 'normal thing'. In other words this family are very open and are acknowledging rather than denying the inevitable death of the children's father.

In summary, the caring role was one of managing and surviving. Managing finances, borrowing money against the equity in the house with no security for the future, surviving on basic benefits (and struggling to work out what they were entitled to), juggling their careers in an attempt to keep the family finances afloat, and for most, eventually sacrificing financial security to become a full time carer, as well as ignoring their own health. Family life also suffered, and families with young children and those caring for more than one dependent were particularly at risk. Overall, the caring role was multifaceted and incredibly challenging.

7: Carers Coping Strategies

Carers devised multiple ways of coping with their situation in order to survive. For many, managing communication and their own emotions was challenging in the face of cancer recurrence. Carers talked about the benefits as well as the limitations of counselling services. Getting time off from caring was something that was highly valued but difficult to achieve. Time off from caring enabled the carer to recharge their batteries and feel refreshed. However many carers felt ambiguous about having time to themselves, leaving their spouse or family member to be cared for by others.

Managing communication

Some of the carers talked about how they managed communication with their dependent. Avoiding talking about difficult subjects and emotions was a way that spouses could protect themselves and the person they cared for:

Interviewer: Are you able to talk about how you're feeling to John?

Carer: No. I don't want to upset him. I think it's been difficult enough for him to accept... He thought he was in remission. I didn't have the heart to tell him brain cancer is incurable. I knew that right from the start. (Wife 6)

The carer talks about how John thinks he is in remission and how she doesn't want to communicate the bad news that his cancer is incurable.

For others, the relationship remained emotionally open and one carer reported how they cried and laughed together, particularly early on in his disease:

We cried and we've had lots of giggles but we used to sit there and hold each other and cry and just..... I think its almost like you have to go through, and this is what I feel like, like I've gone through a bereavement and I've gone through all the stages of anger and denial and guilt. There was like, oh why didn't I know he was getting this, especially when you're a nurse, and I think I've gone through all those and I think I've come to that final state, I think it's acceptance in bereavement isn't it? (Wife 19)

This carer talked about the emotional openness that exists between herself and her husband. She describes how they have cried and grieved over the very difficult situation that they found

themselves in, which she likened to a 'bereavement'. She describes some level of guilt at not knowing her husband was developing a brain tumour especially as she is a trained nurse, but now she has come to a sense of accepting the situation having been through the various stages of grief she now describes 'that final stage'.

Specialist counselling services

Many carers were offered formal counselling at the beginning of the treatment cycle. One carer had taken up counselling over a number of years and found it very helpful:

I have had quite a lot of counselling. I did get to see a lady up at the SH quite a while ago, on and off, probably over a period of about 3 years and when I was having a bad time I could call her up and go and see her. I did find that helpful. (Wife 14)

Some carers went for counselling at the beginning of treatment with their spouse:

I think I needed.... Not counselling. I did have some counselling to start off with. I haven't got time to know that I'm going to sit and cry for an hour you know... and then I have to go and pick the kids up from school. You know that's not me and my life. It wasn't helpful. My children didn't want it. My daughter said unless anybody's going to tell me it's not happening. That's the only thing that is going to help me (Wife 1)

This carer found it was difficult to fit in going for counselling with doing the school run. Also she expresses that it is not something that fits into her life and at that time, she did not find it helpful. Her daughter was also reluctant to accept counselling as she didn't think that it would be useful to her.

In the next data extract the carer describes how she and her husband had mixed reactions to counselling. Although she felt it did help her to understand that her husband had lost his independence. However, she would have liked more practical advice about the cancer and how to explain the situation to her very young children:

We saw the counsellor and she was lovely, really nice but I couldn't get counselling on my own – the waiting list is astronomical also we went three times and we both agreed that we weren't going to go back because we came out of there in despair. It wasn't as positive as I thought it was going to be; it wasn't as upbeat. OK they are counselling you for a reason but not once did she counsel us about the cancer. I want to know what I tell my children, how do you tell a five year old – how? ... We need to know how to

deal with our lives as a family and how to move on and how we cope and what sort of support and things. The only useful thing she made me realise was that Phil had lost his independence. Yes, ok I knew he couldn't drive and I knew he couldn't work but that wasn't a problem because Dad was helping financially and I'd take him wherever he wanted to go. That's the way I saw it but then of course I didn't swing it and see that he had lost his independence and his purpose – that's the only thing that I got out of that counselling session and we just came out of there thinking why are we bothering? We are coming out of here depressed.....(Female Partner 8)

This carer found that the counselling was making her more depressed and she would have liked more information about the effect of cancer on their lives as a family. Also there is a suggestion that she would have preferred to have time on her own with the counsellor but due to long waiting lists this was not possible. This carer talked about how her small daughter expressed a lot of anger and she had difficulty dealing with this.

The daughter of a patient from another European country describes the importance of family and how she felt that they did not need psychological services such as counselling:

We didn't feel like it but I think because we have different psychology as ethnic people because I know the environment I was raised in is a little bit different. I mean we're nothing exclusive but we very relaxing family in people. We have very relaxed views of life so it helps us that's maybe why we don't need this psycho things but I think maybe many people would need that we have met so many people upset and sad and crying in the hospital just sitting in the out patient area so I think it wasn't because of the headaches rather than heartaches, soul aches. (Daughter 4)

This carer had a very close knit family and didn't really believe in counselling as it is unusual in her cultural context where families support each other and have 'relaxed views of life'. Perhaps psychological services are not available in the cultural context that this young woman comes from. In her cultural context the family would be the mechanism of support for someone who is ill.

Another carer talks about his distress in relation to caring for his wife who has a left sided weakness and profound personality change:

if you then add on the personality changes on top of that then no, there's only glimpses of the person that I married. It's depressing..... I've lost it a few times over it, you

know, had a mini breakdown, broken down in tears, but that's only understandable. I've got a season ticket at Arsenal and I had that prior to Poppy.....so it means that I get regular visits or get an excuse to go out and just get away from it and the family will cover those periods (Husband 2)

This carer was not receiving any supportive visits from health care professionals although his teenage son did have support from a hospice professional. This man reports how he has emotional problems related to his wife's condition. He talks about how he had a 'mini breakdown'. He also said that he has no one to talk to about his difficulties. The only time out of the caring situation is when he goes to a football match and this gives him an excuse to get out. There is some evidence that male carers may not have their emotional needs recognised by health care professionals and this needs further research.

Having Time Out from Caring

Having some time out of caring was vital for carers well-being. Even small, everyday tasks that relieved them temporarily from their caring role played an important role in enhancing their quality of life.

However some carers had been together for such a long time that they did not want to be separated:

We've always been together we've know each other since we were fourteen. We celebrated our 40th wedding anniversary last year, which is something I didn't think I'd see and we've always been inseparable really and it never worried me not having time to myself. I mean if I want to go into Sutton I can, and he just gives me a ring on my mobile. If he can get out with me he'll come. When we're in the caravan it will be lovely as we can go for a drive, I'm not sure about his walking anymore. The hospice said they'd lend us a collapsible wheelchair if we needed it. But he doesn't want one at the moment he's independent. He does use a stick now when we're out. We're fine though. We've never been ones to really have separate interests. (Wife 6)

This couple have always done things together and she describes herself and her husband as 'inseparable'. She is looking forward to time away together at the caravan with their dog. Fortunately this carer has always done the driving as her husband doesn't drive, which means there is not problem driving to their caravan on the coast.

Another carer found it difficult to leave her husband for any length of time but she found dropping the children that she minded at school was a break:

(doing the school run) although it was stressful, it gave me the opportunity to get out... Matt knew I would be out for half an hour but I felt I couldn't go for longer or anything.... I've been out once now since he came home from hospital. Just for a walk.
(Wife 1)

Maintaining independence through providing their dependent with transport so they too could have some 'time out' from their relationship helped one carer:

So we bought one of those electric scooters so now I can say to Charlie you go up the veg aisle and choose that and I'll go down this one and that gets us apart from... certainly with the shopping it gives you a little room apart and Charlie can actually go and choose something instead of you pushing him (Wife 15)

And another carer spent time doing DIY and this gave him a break from the caring situation:

I've been putting insulation in the loft so that's been stopping me going crazy... it's not my hobby but it's my release because it needed doing. I couldn't afford not to. But in hindsight I suppose it has been the only release because I say to them what do you want for food, I get it ready and I say 'right, I'm not available for two hours' ... (Father 5)

This DIY activity functions as a break from caring and stops the carer 'going crazy'. Insulating his loft gives him 'authorised' time out from his role of caring for two dependents: his wife and son. During the two hours of DIY he remained undisturbed and free from his caring role.

Another carer describes the luxury of staying with her friend for a few days break:

And when I was going to be away I arranged with different people that he would have a visitor every day and my son went and he was totally in a different view when he saw what it was like. Oh, that few days with my friend was wonderful. I couldn't believe it the first day when I got there we had lunch and I was sitting later in the afternoon and we were chatting and I looked at my watch and I remember saying to her, is it only that time? Because it seems my whole life right now is do this before I've got to do that or before that or before somebody else is coming in. We are getting visits from district nurses and different people all the time. She said to me, look, get up when you like,

doesn't matter what time you get up, stay in bed till lunchtime, doesn't matter and I did. One day I got up at 11 o'clock. At that stage I wasn't having a bath, I didn't have time. My son said 'does Dad have a shower every day?' and I said 'no, and I don't? He thought that was disgraceful. He said 'you can't find 20 minutes?' I said 'no'....laughter (Wife 23)

This carer describes the wonderful few days away from her caring role relaxing with her friend. She has made arrangements that her husband has visitors every day. Also her son who was with his father began to appreciate the work that his mother is doing caring for his father. The sheer demands of caring, coping with visits from health professionals and other caring activities means there is so little time for the carer to unwind and relax. Therefore her time off from caring was described as 'wonderful' able to relax and chat with her friend.

Another carer was planning a holiday away without her husband so that she and her child could have uninterrupted time together:

This summer for the first time since he's been ill I'm going on holiday without him to do something with Emily and my family because he doesn't want to fly on a plane..... I've felt for the past five years, I know it sounds awful but I've kind of put Tom's needs first and I thought I've got to do something for Emily and myself. I need a week away to recharge my batteries and I don't think it's unhealthy at all... that's a plus for us (Wife 19)

This carer expresses the importance of spending time alone with her daughter and not feeling guilty about it. For five years she has put her husband's needs first but now realises she needs to do something for herself and her daughter.

Facing the Future

Many of the carers alluded to the future and their concerns. For some, the patient was very aware of their own mortality. These patients were able to support their carer by talking openly about their death. One carer describes how her husband talks about dying:

'I'm dying aren't I?' and I said 'we all are aren't we. We're all born and we all die', and he said, 'no, you know what I mean'. And when I told the GP and he said, well at least he's accepted he is, and he's not pushed it to the back of his mind he's admitted to

you. I know it's hard for you but that's one goalpost that we've got past and if he's accepted that. He's been really good about it, but I think it was such a shock when they said the cancer had come back aggressively. He keeps saying to me 'are you going to cope?' and I say, 'you know I will, you know I've always been strong'. ... I've always been a strong person.. I am coping... (Wife 6)

This couple are very close and it is a very difficult situation for this carer who has known her husband since she was fourteen years old. However her husband is checking with her and showing his concern for how she will cope after he has died. The GP sees this as evidence of her husband's level of acceptance of his situation and in that sense he describes it as a 'goalpost' that they've got past.

Other carers learnt to take each day as it comes and avoided thinking too much about the future and found this to be an effective coping strategy:

Taking each day at a time. Don't look forward too much into the future because this is where I think I used to go wrong to begin with. I used to plan for things way ahead, but now, With Tom his tumour is quite unusual in that it's re-grown... but I just don't try to think about it too much – that's how I have to be. (Wife 19)

Taking one day at a time and avoiding looking to the future was an effective strategy for this carer particularly as her husband's tumour has re-grown and he was no longer in remission.

Another carer describes how her husband remains optimistic and is remaining hopeful for the future:

He's still got hope which I think does help despite the prognosis and everything. You've got to have something which keeps you going and he's a very determined person but it is hard to know what to say sometimes. I don't want to be sort of pessimistic he'll die,... there are long term survivors of this tumour you just don't know do you. (Wife 10)

Having hope is considered helpful by this carer and keeps things going. Her husband is reported to be hopeful and determined. However this can be difficult for the carer because her husband's level of hope may not match her own as she finds it difficult to know what to say at times. The not knowing and the knowledge that there are survivors of the tumour helps her to

some extent. Not knowing can help with keeping hope alive. Another carer describes the unknown as very unnerving:

And that I find is the most frustrating and unnerving thing. It's the unknown...This is the thing. I wouldn't tell him but if I'm out, well I don't get out much but if I'm in a clothes shop and I see something, particularly now, fashion seems to be black and white and I must say I'm looking and I've got half a thought on - that's nice, wonder if it's worth buying that, I might need that soon. I mean....and there are times when I think when is this going to stop. This whole life I've got and then I feel so guilty because it can only stop then, you know. And then I feel bad about that. At the beginning when he was diagnosed there was no qualms about it. He was in a terrible state and I said to him I am with you all the way, we'll fight this and I'll look after you and all that. But I thought it was going to be for.....the thought that it could be for years, I don't know that, I still don't think it will but it puts a different perspective on it. I am so tired...(Wife 23)

This carer's initial reaction was to help her husband 'fight' and overcome the situation but as time has gone on she realises how tired she is and not knowing how long she will have to care is 'unnerving'.

In summary, carers employed a range of coping strategies to deal with their everyday lives. Coping with the psychological and emotional aspects of caring for a terminally ill family member were extremely challenging. Some carers carried the burden of their loved ones illness and protected them from the full horror of their prognosis by filtering bad news. This placed an untold burden on the carer who ended up carrying the emotion for both of them. Other carers were more emotionally open with their dependents and they shared the burden through both tears and laughter. Together, these carer and dependent teams coped by achieving some level of acceptance of their illness. Some carers consulted counselling services and this had mixed reviews. Overall, taking time out to unpack their emotions with a counsellor sometimes did more harm than good, and left them feeling even more despairing. As one carer mentioned, they would prefer more practical advice.

Support from family and healthcare professionals was very important in helping the carers cope. For one carer, this support was lacking, and this resulted in a 'mini breakdown'. Most agreed that their ability to cope was improved if there was the possibility of taking some 'time out' from their caring role, although one carer explained that they had always done everything together and they didn't want this to change in sickness. Carers took time out where they

could, dropping the children off at school, doing DIY, going away for a few days with family or friends, and these were all found to be beneficial.

Facing the reality of the future was challenging for all carers. Some coped by not thinking too much about what the future held, and 'taking one day at a time'. Maintaining hope, by not thinking about the future was an important coping strategy.

8: Discussion

The caring journey is one that is all encompassing, fraught, exhausting, unnerving, as well as rewarding. During their initiation into the caregiving role carers slowly become aware of the enormity of the caring task that confronts them. They begin to realise that they must look after their own needs, if they are to continue to care for their family member. They also start to understand their responsibility in organising and orchestrating the care for their family member. The carer has to learn to deal skilfully with a number of demands, including significant psychological and social changes that have often been present for some time before the diagnosis. Coupled with the physical changes associated with a PMBT are the emotional changes associated with the shock of receiving the diagnosis, news of a poor prognosis and treatment schedules that result in extreme tiredness and lethargy for the person with a PMBT as well as changes in family dynamics. Furthermore the demands of practical caring for a disabled dependent can take a physical toll on the carer and their own health can be put at risk. The family caregivers in this study have an intense emotional investment in their dependent and both suffer as a result of this devastating and unexpected illness. All of this is often occurring in a short timeframe with a swift decline in patient's behavioural, physical and psychosocial functioning. In the next section the research questions and relevant findings will be discussed.

To what extent are carers' needs identified?

To a large extent, the proactive identification and assessment of carers needs separate to their dependent are largely overlooked. Only one carer in this study reports a full assessment of her needs, with a care manager allocated to her (carer 23). Many carers were in an unenviable situation, where they were reaching breaking point, as their family member's condition deteriorates, before their needs are identified. Therefore, attending to carer's needs tended to be a reactive or a fire fighting activity, often at a point where the care situation was in danger of breaking down. For example, one carer was urged by her Marie Curie nurse to demand more help for her terminally ill husband: 'the Marie Curie nurse came, she said you must ask for help you have got to ask for help' (Carer 1). Another carer describes how she had broken down on the district nurse: 'And it was just too much and I broke down with the district nurse and I said look I do need some help' (Carer 10).

It is unclear at the moment in the mixed economy of health and social care as to who is responsible and accountable for assessing the needs of carers. Carers report the lack of individual time from healthcare practitioners allocated to them alone, without their dependent present in the community. As the demands of caring for someone with a malignant brain tumour at home is so great, it is imperative that where there is cognitive decline and personality changes, and as the patient's condition deteriorates that community staff regularly assess carer needs and concerns. A key worker should be allocated, to take responsibility for assessing carer needs and provide packages of support. The support needs of carers should be documented and made accountable and a plan actioned in the weeks following diagnosis by the appointed key worker in the community.

How do carers access information and how helpful do they find it?

Carers report they have needs related to information about managing medications such as steroid therapy. Problems with short memory loss meant that carers had a great deal of responsibility in monitoring side effects of therapy and calculating drug doses. A number of carers reported insufficient knowledge of the side effects of steroid therapy. Carers were also concerned about changes in sleep patterns, how to manage lethargy and extreme fatigue. At the present time carers do not receive enough information from community palliative care staff about managing fatigue.

It was expected that there would be informational needs related to seizures. However, carers seemed to accept that seizures were inevitable. Following a seizure there was usually an emergency admission to hospital followed often by a brain scan to detect changes or recurrence and a review of anticonvulsant medication. The concern for carers related to seizures was the risk of falling and injury. Falls was a considerable worry for spouses who worked (carer 6). Other carers worried about getting their spouse off the floor should they fall especially when they had a weakness on one side. Where the person with a PMBT did have a fall the ambulance service had to be called to help get their dependent up (carer 9, carer 23). Carers needed help in how to prevent and manage falling.

Many carers felt unprepared for the role that they took on, and would have valued a mentor or guide who is experienced in caring in order to prepare them for their new 'job'. One carer mentioned that there is no manual or job specification explaining how to be a good carer. Finding information and executing the role was dependent on trial and error. Furthermore, the

dynamic nature of having a brain tumour meant that the day to day and week to week changes in their dependent's health, personality and memory capabilities, presented new daily challenges for the carer. Two carers expressed the need to meet someone else in the same situation as themselves. For example carer 18 would like to meet up with another couple in the same situation and carer 22 would like to meet with another carer who could prepare her for the role she was taking on.

Managing personality and cognitive changes such as short term memory problems were a major challenge. Carers received very little help with these problems and resorted to common-sense strategies such as humour, association techniques, trying to be more patient and re-taking repeated questions as if for the first time. There is some evidence that carers could be stretched beyond their ability to cope with these problems and to suffer major emotional upset. An emerging hypothesis from this study is that community palliative care nurses may not have practical skills and knowledge in helping carer's manage behavioural problems and cognitive problems.

What concerns do carers have?

Although carers both men and women took on the caring role they meet difficulties like their own tiredness, feeling run down because they had no time for themselves, and reacting to the changing needs of their dependent. The carers who had to cope with the most demands were those with other dependents such as school age children. One carer was caring for his wife who had Parkinson's Disease and his son with a PMBT. The complexity of caring for more than one dependent meant that the carer had to balance many more demands with very little time out from caring. In these situations there were many more tasks to perform in the home, such as preparing meals, attending hospital appointments, and school runs. In a study of thirty-nine informal carers of people with cancer Payne et al (1999) report how younger female carers experienced more stress than older carers. In the present study five of the carers with young or teenage children reported considerable emotional upset (carer 1, carer 12), low mood (carer 10), loss of weight (carer 15) and feeling at breaking point at times (carer 2). In this study male carers also report considerable upset and distress in relation to their caring role particularly those with two dependents (carer 5), caring for a disabled wife and teenage children (carer 21), caring for a wife with significant personality changes, mobility problems as well as a teenage son (carer 2). One of the emerging hypotheses from the study is that the psychosocial support for male carers, although similar to female carers in terms of emotional

upset, are overlooked as male carers may not identify them to healthcare professionals in the same way as female carers.

Many carers are concerned about financial issues and problems with accessing sufficient information about benefits. The financial implications of giving up work for full time caring are under reported, and the stress that these can add to the caring role often go unrecognised. Very few patients or carers had insurance cover for ill health. Two of the female carers with school age and younger children found the benefits system very difficult to negotiate. Both these carers felt a great need for more support related to accessing benefits. One carer had found an excellent contact in her local carers group (carer 15). Carer 15 identified the poor quality of information available at her DGH in contrast to that available at the specialist hospital where she was allocated a CNS who could give her good quality information. This contrasted sharply with her previous experience.

What emotional and social support do carers receive?

Having good support systems such as people who could come and sit with their dependent if there were issues related to safety for example was a life line for carers, as it enabled the carer to get out and have time out from caring. Locating good support early on in the illness trajectory and building a good relationship with this person did much to alleviate the caring role. Marie Curie nurses, who were available to nurse terminally ill patients in the day and night, were praised (carer 10). These nurses could coach the carer to feel confident to demand more help, which worked to legitimate the carers needs (carer 1). Other services that were useful were day hospice (carer 14), the hospital and hospice carers support group was also beneficial to give the carers somewhere to go and talk with others in a similar situation.

Friends and family gave an enormous amount of help, most importantly, they provided the carer with somewhere to go both physically and emotionally. However, there could also be tensions between the generations most notably in this study between parents in-law and female carers. One carer describes a deterioration in her relationship with her parents-in-law due to their lack of acceptance of their son's changed personality (carer 19). Tension between female carers and in-laws was also mentioned by carer 10 and 14. This issue needs further research and demonstrates the tension that cognitive and behavioural changes can have on family dynamics. For one carer, a solution to the situation was in establishing a triage of care, with the carer supporting the PMBT patient, and in turn, the daughter supporting her mother, the

primary carer. This reciprocity in care has been described by Thomas et al (2002) who described the caring relationship as one of co-dependence and reciprocity rather than a dependent relationship.

Many carers spoke about their close relationship with their loved one. For some carers their relationship had become stronger despite the changes in behaviour and personality of their partner or relative (carer 19). This closeness is also reported by Cook (2005) in a small interview study of five carers of people with a malignant brain tumour. In a study by Thomas et al (2002) informal carers are reported to have little choice about engaging in difficult emotion work to help the person with cancer and to manage their own emotions. In this study there is evidence reported by the carers that the person with PMBT also manages their emotions by being upbeat (carer 5), optimistic about survival (carer 11) and taking openly with their partner about the inevitability of dying (carer 6), and showing concern for how their partner is coping (carer 6, carer 19).

Of some concern is a reported loss of the intimate, sexual relationship between couples. This was reported as a significant loss that is mourned by carer 10. Carer 14 reports significant problems with sexual functioning on her part related to her husband's changed personality. She reports that as a couple they have not sought help with this problem and her intimate relationship with her husband is severely affected. This carer also reports having problems with depression and has found counselling effective over many years of caring.

Although it is reported that carers consider their own needs to be of secondary importance (Morris and Thomas 2001) a number of carers in this study would like to have time on their own with health care professionals to seek advice and support separate from the person they are caring for. This is an important finding in this study as carers wished to avoid upsetting their loved one and often felt they couldn't ask questions in front of their dependent. One carer suggested it would be helpful to meet another carer and to be mentored in the caring role and have help with the practical tasks of caring.

What coping strategies do carer's utilise?

There was a notable difference in this study between carers who had been in the role for some years and those who were new to caring. The carers who had been coping for many years had learnt coping strategies for dealing with both practical and emotional issues of caring. For example the more experienced carers talked about taking one day at a time and avoided

thinking about the future. They were able to demonstrate their ability to give care such as diagnosing infected wounds, preparing meals and coping with short term memory problems. They were also able to stay hopeful. They described pride at the unexpected survival of their family member. They also described the optimism of their family member who were up-beat and uncomplaining despite living with a poor prognosis. There were negative aspects related to the psychosocial and emotional burden on the carer of long term survival. A few carers admitted to suffering from depression and frustration with the person they were caring for and the significant changes in their personality and motivation to achieve tasks in the home. These carers needed the support of a significant person outside of the home to talk to. Some carers had accepted counselling services but some male carers were not receiving as much support as would be expected, particularly from specialist palliative care services.

Many carers identified their central role as 'leader' in the care arrangement: 'just lately everyone looks to me for help and advice to do this and that' (carer 10). Thus in the home setting the primary carer who was normally a husband or wife had to orchestrate and coordinate a number of secondary carers, depending on how ill their dependent was. Some carers were very adept at organising services to help with the caring role. This was particularly evident when they had someone to guide them such as a clinical nurse specialist, another experienced carer or close friend who had experience of being a carer; or Marie Curie nurses who understood the demands on the carer when their family member is dying.

Those that were new to caring sometimes voiced that they wanted to do the caring themselves particularly in the early stages of the disease. Those new to caring were often aware of the support services available but had yet to take advantage of them. Or they accessed services in an ad hoc way. Some carers felt guilty about handing over care to other people therefore were reluctant to ask for practical help. There is evidence that carers waited until they felt they were not coping before they accessed help. Only one carer describes having a care manager and had her needs assessed. Two carers discussed the difficulty of not knowing what the sequence of events would be in the illness and what changes to watch for. One carer described the uncertainty surrounding her husband's future as 'unnerving'. Her husband has now survived beyond his predicted survival date (carer 23).

In the present study a number of carers did point out that they were coping by using a strategy of denial. Carer 17 was searching for new treatments on the internet and thinking about having a second opinions. Carer 2 also suggested that he and his wife were in denial and for this

reason found it difficult to engage with specialist palliative care staff. Rose et al (1997) found that 'togetherness' and 'partnership' were the most helpful coping strategies engaged in by carers of people with cancer. Although carers in this study did refer to having a close relationship with their spouse or partner this was made difficult by the cognitive and personality changes associated with PMBT. A number of carers used a protective strategy of 'being strong'. Salander et al (1996) report how carers avoided talking openly in order to maintain hope. This strategy of not talking openly was referred to by a number of carers in the present study. However, one female carer felt she would like to talk more openly with her husband but he refused (carer 23). Another carer's husband wished for more open communication and challenged his wife's avoidance of talking openly (carer 6). Not talking openly is a coping strategy that enables the carer to manage both his/her own and the spouse's emotions related to recurrence and a poor prognosis. One daughter was committed to playing the 'open game' and felt that this was the only way to cope with the situation in a triad of caring: father, mother and daughter (carer 4).

Conclusions

One of the overriding features evident in this study, was that the emotional toll and the physical labour that went into caring for a loved one with a PMBT. As in other forms of care work the emotional labour that goes into caring remains largely invisible and hidden from view. Thus in this study many carers expressed how unheard and invisible they often felt. Carers report a lack of acknowledgement for the important role they carry out, sometimes even from within their own families where they are largely taken for granted. Whilst the carers were not seeking accolade or reward they wanted the importance of their role to be recognized, and their needs addressed. Carers are ultimately doing hard physical and emotional work to keep their dependent comfortable and meet their dependent's needs. However carers report that they have little access to support for themselves.

For some having someone they can talk to outside of their immediate family was important such as a buddy or friend who could help them in the tasks of caring; for others a guide who is an experienced carer who could help them in understanding how to give care, and for others help with talking to their children about their mother or father's serious ill health. Having time off was essential to the well-being of the carer. It is very worrying that some carers who were caring for more than one dependent were unable to have respite from the caring role. Carers

were reporting a number of physical health problems that could endanger their caring role. This is a serious concern for both carers as well as services as without these carers there is no care in the community. There is some evidence that male carers may have less support than female carers as they may not have the same networks of friends and neighbours as female carers.

Recommendations

This study supports the importance of a designated CNS in neuro oncology in all treatment centres. Furthermore there are learning needs for specialist community staff in the management of cognitive and personality changes, fatigue, falls and building therapeutic relationships with carers:

- It is imperative that all treatment centres have a hospital based CNS in neuro oncology, as this role makes a significant difference to the quality of information and support that patients and carers receive
- Identification of a key worker in the community who takes responsibility for assessing carers' needs and monitoring the quality of social service support
- Training for carers in managing behavioural and cognitive problems, managing falls, fatigue and managing medication in particular steroid therapy
- An appraisal of the training needs of community palliative care nurses and district nurses in providing carer support, managing fatigue, and managing cognitive, behavioural and personality changes

Section 2

Audit of case notes

Audit of case notes of patient's with a primary malignant brain tumour

Introduction:

The aim of the audit of patient's notes is to identify access to care, support services and rehabilitation services for patients with a primary malignant brain tumour (PMBT). Previous work demonstrates that patients with PMBT do not access some services in particular day hospice services and this could be for reasons related to the frequency of cognitive problems in this group of patients (Faithfull et al 2005). Another aim for the audit was to ascertain the degree that specialist palliative care staff document information related to home carers. The carers of those with a PMBT have many caregiving demands to deal with due to the complexity of patient's symptom profile. Therefore assessment intervention and documentation of the support given to home carers is extremely important in this care context

Audit Objectives:

- identify patient and carer access to specialist and non-specialist services
- Identify the range of support services used
- What symptoms are documented in patient's notes?
- What is documented in relation to carer needs?

Method:

This is a retrospective review of 70 patient's case notes who received specialist palliative care over a period of one year. An audit tool/proforma (Appendix 5) was developed based on previous pilot work carried out by Faithfull et al (2005). Five specialist palliative care locations were audited. Case notes of all those with a PMBT were selected between 1st July 2005 and 30th June 2006 from five hospice and specialist palliative care centres. One person, a research nurse, collected the audit data to enable consistency in data collection. The data was entered into SPSS and descriptive statistics were generated. The sample size was too small to run statistical tests.

Data collection

The audit data collected included location of care, demographic information, symptoms experienced and services utilised, and place of death (see Appendix 5).

Location of care

Audit data were collected from five locations, which are shown in Table 1. The Princess Alice Hospice had most cases of PMBT between July 2005 and June 2006. Woking Hospice had only 2 sets of case notes.

Location	Number	Percentage of total
The Princess Alice Hospice	28	40%
St Catherine's Hospice	16	23%
Phyllis Tuckwell Hospice	13	19%
Beacon centre	11	16%
Woking Hospice	2	3%

Table 1. Location of Specialist Palliative Care (SWSH)

Patient Demographics and diagnosis

The median age of the sample was 64 years with 56% (n=39) men and 44% (n=31) women (Table 2). The majority of patients had a diagnosis of glioblastoma (59% n=41), with 21% (n=15) astrocytoma, and 6% (n=4) oligodendroglioma. 10% (n=7) of patients had no confirmed diagnosis.

Demographics: Age and Gender	
Age	Range in years 21-94 Median years 64
Gender	Male 56% (n=39) Female 44% (n= 31)

Table 2 Median age and gender

Who was the main carer for the patient in the community?

Forty three (61%) patients were married or co-habiting with a partner. The majority stated that the main carer was his/her partner (60% n=42). Fourteen patients (34%) were divorced, separated, single or widowed. Other primary carers were named as children (7% n=5), other relatives e.g. sibling, niece (5% n=4), parents (4% n=3) or were cared for in a nursing home (13% n=9).

It was difficult to identify carer's needs and problems from the information available in the clinical case notes. However there was information documented if the carer was distressed, which is identified in Table 4. This suggests that staff may only document information about carers when there is significant emotional upset.

Illness trajectory: symptoms requiring palliation

Problematic symptoms and care problems experienced by patients were clearly identified in the notes and these are identified in Table 3.

Symptoms		Care problems	
Hemiparesis	17% (n=12)	Speech difficulties	11% (n=8)
Cognitive state	16% (n=11)	Poor mobility/ falls	9% (n=6)
Dysphagia	7% (n=5)	Carer distress	5% (n=7)
Headaches	4% (n=3)	Agitation	4% (n=3)
Nausea and vomiting	4% (n=3)	Unable to take medicines	3% (n=2)
Incontinence	4% (n=3)	Psychological issues	3% (n=2)
Extra pyramidal symptoms	3% (n=2)	Syringe Pump	1% (n=1)
Seizures (Epilepsy)	3% (n=2)	Other	33% (n=23)
Tiredness/ sleepy	1% (n=1)		

Table 3. Symptoms and care problems

The two significant symptoms for many patients were hemiparesis and cognitive problems 17% and 16% respectively. In addition a number of care problems concern safety related to mobility and falls. Symptoms such as fatigue and tiredness seem to be very unusual with only one patient identified as having a problem with tiredness. Tiredness and fatigue was one of the most common symptoms identified by carers in the interview data. Fatigue and tiredness appear to be under-reported by patients in contrast to carers. There is a possibility that this symptom may not be identified by staff during symptom assessment.

Carer distress was documented as a concern for 3 (7%) but this was not cited as a reason for the patient's admission to an in-patient unit and this did not appear to be related to symptom profiles.

33% of patients (n=23) had additional problems documented under 'other' such as terminal care, chest infections or facial swelling. The data from the case notes highlighted the complexity of patient symptom profiles with 39 (56%) patients having one or more symptoms and 7 (10%) patients with four or more symptoms.

Service utilization

Of the 70 patients, 20 (28%) were admitted to the hospice in-patient unit. Eleven (15%) patients were admitted to other acute inpatient services. Information was not always available about the reasons for these admissions. 8 (11%) attended outpatient appointments. The majority of these were at acute or rehabilitation units. This figure is lower than that identified in the original pilot data conducted by Faithfull et al (2005) suggesting that hospital outpatient appointments for follow up care has reduced.

Table 5 below identifies the range of services that patients have accessed.

Services	Number	Percentage
District nursing services	35	49%
Social services	25	36%
Physiotherapist	25	35%
Counselling services	25	35%
Occupational therapist	22	31%
Complementary therapy	17	24%
Day hospice care	17	24%
Chaplains	9	13%
Speech therapist	7	10%
Voluntary Services	5	7%
Dietician	3	4%
Support groups	2	3%

Table 5: Services utilised

Within the community 35 (49%) patients accessed district nursing services. 5 (7%) accessed other voluntary based services; these were either the Marie Curie sitter service (3), Macmillan nursing services (4) or twilight nursing services (1) with several patients accessing more than one. Only 17 (24%) attended day hospice. 25 (36%) patients were referred to social services and this probably reflects their need for help with activities of daily living such as washing and dressing. Many patients 57% (n=40) accessed rehabilitation services, predominantly physiotherapy (n=25, 35%) and occupational therapy (n=22, 31%).

A number of patients (n= 24, 34%) received financial benefits. These benefits were documented as being mainly disability and attendance allowance (n=14, 20%). Complementary therapies mainly massage and aromatherapy were used by 17 (24%) patients and carers. It was unclear from where these were accessed. However these services are often offered by hospices.

There was little evidence that patients or their carers accessed support groups (n=2, 3%). This could be because this was not assessed or documented by staff. Or perhaps support groups are

not available, this needs further investigation. Twenty five patients and carers (35%) utilized a counselling service with this focused on bereavement services (18.3% n=13), or individual patient support (10% n=7), Only 9 (13%) accessed chaplains or had ongoing support from their local/own church, or perhaps this sort of detail is not normally documented in the case notes

Place of death

Details of place of death were available for 55 (79%) patients; the remaining patients had no available information about whether they were still alive, or if deceased place of death. Of the patients who died 21 (30%) died at the hospice, and 11 (16%) died at home, 14 (20%) died in another hospital, 9 (13%) died in a nursing home, 15 (21%) have an unknown place of death with no documented information about whether they were deceased or of continuing status.

Place of Death	
Hospice	30%
Hospital	20%
Home	16%
Nursing home	13%

Table 4 Place of death

For this group of patients the number dying in hospice is high compared to those dying in hospital. Age differences in relation to location of death were seen with older people more likely to die in a nursing home and younger people dying in a hospice.

Of those who died, the time scale between diagnosis and death was a median of 130 days (18 weeks) with an IQR range of 47- 330 days. Of the 55 who had place and date of death documented, time from diagnosis to referral to the palliative care team was a median of 80 days (11 weeks) with an IQR of 17- 193 days. Of these, the time range between referral and death was a median of 62 days (8 weeks). Local variation was evident in the time between diagnosis and palliative care referral; with a median of 66 days at The Princess Alice Hospice, 71 days at St Catherine’s Hospice, 46 at Woking Hospice, 106 days at Phyllis Tuckwell Hospice and 105 days at the Beacon centre. This may reflect local variation in CNS provision and referral pathways.

Conclusion

Details related to carer assessment are not routinely documented in patient's notes by specialist palliative care staff. However, there is some indication that carer needs are identified if there is significant carer distress, this may reflect a reactive approach to carer needs rather than a proactive approach. The absence of a focus on the home carer is problematic and this may be a resource issue for specialist palliative care staff.

Problems such as fatigue and tiredness appear to be rarely documented with only one patient having this symptom documented in the notes. Yet this is known to be a prominent symptom in patient's with PMBT. Perhaps carers are more aware of the problem of fatigue and report it more than patient's do. This is something that needs further investigation. There also appears to be little use of patient support groups and this may reflect the availability of such groups, or problems in using these groups due to mobility and cognitive problems. Similar to the findings of Faithfull et al (2005) only 24% of patients used day care services.

About half of patients use district nursing services and this is lower than the previous audit where 72% of patients had access to a DN. Also the figure for using social services is lower at 36% compared to 46% in the previous audit. This is of concern as there could be less availability of DN support and social service support. A range of rehabilitative services are accessed by patients predominantly physiotherapy and occupational therapy, with very few patients accessing speech therapy. Surprisingly no patient has a social work referral but about a third of patients have access to counselling services. It would be useful to compare the use of counselling services with the take up of counselling in other cancers with a poor prognosis.

One key difference in this and previous audit data is that the large number of outpatient appointments are considerably reduced and this is an interesting finding over the two years since the Faithfull et al (2005) audit.

In contrast to the previous audit where 33% of patients died at home, the figure for this audit was only 16%. There was some missing data related to place of death for 15 patients. So the accuracy of recorded data is an issue here.

In relation to recommendations for documentation, it is important to identify the range of support services that carers and patients have been offered as well as the uptake of services and

any barriers to service utilization. Until we have got this data it is difficult to understand the context of service use, access to services, and any barriers to using particular services.

References

- Andershed B and Ternstedt B 2001 Development of a theoretical framework describing relatives' involvement in palliative care. *Journal of Advanced Nursing*, 34,4:554-562
- Cook KL 2005 The carers' experience: caregiving for primary malignant brain tumour patients with palliative care needs. Unpublished MSc dissertation, University of Surrey, Guilford, UK
- Eriksson M and Svelund M 2006 'The intruder': spouses' narratives about life with a chronically ill partner. *Journal of Clinical Nursing*, 15:324-333
- Faithfull S, Cook K, Lucas C 2005 Palliative care of patients with a primary malignant brain tumour: case review of service use and support provided. *Palliative Medicine* 19:545-550
- Fox S and Lantz C 1998 "The brain tumour experience and quality of life in patients with primary brain tumours." *J Neurosci Nurs* 30,4: 245-52.
- Fox SW, Mitchell SA, Booth-Jones M 2006 Cognitive impairment in patients with brain tumors: Assessment and intervention in the clinic setting. *Clinical Journal of Oncology Nursing*, 10,2:169-176
- Glaser B, Strauss A 1967 *The Discovery of Grounded Theory: Strategies for Qualitative Research*, Chicago, Aldine
- Grant R 2004 Overview: Brain tumour diagnosis and management. Royal College of Physicians guidelines. *J Neurol Neurosurg Psychiatry* 75 (Suppl 11): ii18-23
- Guerrero D 1998 *Neuro-Oncology for Nurses* London, Whurr
- Heaton J 1999 The gaze and visibility of the carer: a Foucaudian analysis of the discourse of informal care. *Sociology of Health and Illness* 21,6:759-777
- Hackman D 2007 What's the point? Exploring the Purpose of Physiotherapy Rehabilitation for patients with Primary Brain Tumours: A Study of Patients' Perspectives. Unpublished MSc Dissertation, University of Surrey, Guildford, UK
- Harding R, Higginson IJ 2003 What is the best way to help caregivers in cancer and palliative care? A systematic literature review of interventions and their effectiveness. *Palliative Medicine*, 17:63-74
- Hileman JW and Lackey NR 1990 Self identified needs of patients with cancer at home and their home caregivers: a descriptive study. *Oncology Nursing Forum*, 17:907-13
- Hudson P 2004 Positive aspects and challenges associated with caring for a dying relative at home. *International Journal of Palliative Nursing* 10,2:58-64
- Kirk P, Kirk I, Kristijanson LJ 2004 What do patients receiving palliative care for cancer and their families want to be told? A Canadian and Australian qualitative study. *BMJ* 328: 1343-1350
- Kitrungle L, Cohen MZ 2006 Quality of life of family caregivers of patients with cancer: A literature review. *Oncology Nursing Forum*, 33,3:625-632
- Klein M, Taphoorn MJ, Heimans JJ, van der Ploeg HM, Vandertop WP, Smit EF 2001 Neurobehavioural status and health-related quality of life in newly diagnosed high-grade glioma patients. *Journal of clinical Oncology* 19, 4037-4047

- Morris SM Thomas C 2001 The carer's place in the cancer situation; where does the carer stand in the medical setting? *European Journal of Cancer Care* 10:87-95
- Nieder C, Adam M, Molls M, Grosu AL 2006 Therapeutic options for recurrent high-grade glioma in adult patients: recent advances. *Critical Reviews in Oncology Hematology* 60, 181-193
- Nolan M, Grant G, Keady J 1996 *Understanding family care: A multidimensional model of coping and caring*. Buckingham, Open University
- Payne S, Smith P, Dean S 1999 Identifying the concerns of informal carers in palliative care. *Palliative Medicine*, 13:37-44
- Pinquart M, Sorensen S 2003 Association of stressors and uplifts of caregiving with caregiver burden and depressive mood: A meta-analysis. *Journal of Gerontology Series B-Psychological Sciences & Social Sciences*, 58:112-128
- Rose KE, Webb C, Waters K 1997 Coping Strategies employed by informal carers of terminally ill cancer patients. *Journal of Cancer Nursing*, 1,3:126-133
- Salander P, Spetz A 2002 How do patients and spouses deal with the serious facts of malignant glioma. *Palliative Medicine*, 16:305-313
- Salander P, Bergenheim T, Henriksson R 1996 The creation of protection and hope in patients with malignant brain tumours. *Social Science and Medicine*, 42,7:985-996
- Sherwood PR, Given B, Given C, Schiffman R, Murman D, Lovely M 2004 Caregivers of persons with a brain tumor: a conceptual model. *Nursing Inquiry*, 11,1:43-53
- Sherwood PR, Given BA, Given CW, Schiffman RF, Murman DL, lovely M, et al 2006 Predictors of distress in caregivers of persons with a primary malignant brain tumour. *Research in Nursing and Health*, 29:105-120
- Stoltz P, Willman A, Uden G 2006 The Meaning of support as narrated by family carers who care for a senior relative at home. *Qualitative Health Research*, 16,5: 594-610
- Thomas C, Morris SM, Harman JC 2002 Companions through cancer: the care given by informal carers in cancer contexts. *Social Science and Medicine* 54:529-544
- Tucha O, Smely C, Preier M, Lange KW, Klaus W 2000 Cognitive deficits before treatment among patients with brain tumours. *Neurosurgery*, 47,324-334
- Weitzner MA 1999 Psychosocial and neuropsychiatric aspects of patients with primary brain tumors. *Cancer Investigation*, 17:285-289

Appendix 1 Discussion Guide

DISCUSSION GUIDE

EXPLORING THE NEEDS OF CARERS

Introduction

My name is I am a researcher at the University of Surrey, and would like to talk to you about your experiences so far of your role as a carer to your husband/ parent/ child/ friend. I will not be asking you anything personal about yourself, and please only talk about things that you are comfortable with.

The reason we are undertaking this project is to ascertain the information available and the support provided to carers of patients with brain tumours, so that improvements can be made. As part of this, the information you give today is going to contribute to producing a booklet and website that we hope will be available to all carers in the future to provide them with vital support and information - so your contribution is really valuable.

I would like to talk to you for between 45 minutes and an hour, but if you would like to stop the interview at any time, you have every right to do so, and this will not have any impact on you or the care that your dependent receives. I will be recording the interviews, but the tapes will be stored securely, and only used by me and the research team. If you would like to stop the tape recorder at any time, please let me know. We are interested in your thoughts and opinions – there are no right or wrong answers.

Topics to be covered in the Interview:

When was your husband/wife/parent/child/friend given their initial diagnosis?

At that time, were you offered any assistance or information that you can remember?

Have you received or found out any information since then that has been useful?

-if so, what is it?

What information / support if any, would you like to have been offered at the initial diagnosis?

-If not at initial diagnosis, when would it have been a good time to receive this information/support?

What emotional support do you feel you have received?

-when did this start / when would it have been most useful?

What practical and social support have you received?

-when did this start / when would it have been most useful?

Have you received practical information on how to deal with the day to day issues?

-if so, was it useful?

How do you feel about your new caring role?

How confident and competent do you feel in this role?

Have you accessed any specific services so far and how did you find them? UNPROMPTED

Have you accessed any of the following services, when did you access them, and how did you find them? PROMPTED

-specialist palliative care nurses/Macmillan

-respite care

-social care

-general practitioner

-district nurse

If you wanted more information on anything, where would you go?

(Interviewer, establish what type of additional info they'd want for each item mentioned, and then where they'd go)

If you wanted more information how would you like it presented?

e.g. someone talking to you, website, home visit, booklet etc.

What would be the benefits of being more informed?

Is there anything else that you can think of that would have made your caring role easier in anyway?

Thank you and Close Interview

Appendix 2 Research Methods

Stage 1 will involve qualitative in-depth interviews with primary carers (the primary carer is defined as having principal responsibility for the care of their dependent, and who is actively caring for the patient at time of the interview). Data will be collected by semi-structured, tape-recorded interviews conducted in a location convenient to the carer. Where possible the sample will reflect carers of different socio-economic classes, ages, gender and ethnic background.

The interviews will be carried out with carers within a period of 3-12 months since the patient's diagnosis of malignant brain tumour at the **** Hospital.

Discussion Guide

The Discussion Guide used in the interviews will be developed with input from both the internal Surrey research team, and the Steering Group. Topics that will be covered include the carer's perception of support, their satisfaction with the caring role and their perceived confidence and competence in this role. The use and access to services such as specialist palliative care nurses, respite care, social care, general practitioner and district nurse support will be ascertained.

The project team will identify the services currently available and those used by patient's with a malignant brain tumour and their carers. This will enable a comparison between service availability, service useage and any barriers to access to such services. This evaluation of service provision will enable a robust identification of gaps in services available to this patient group and this will be a key outcome of the research.

Data Analysis

The data will be analysed using a grounded theory approach (Strauss and Corbin 1998). The constant comparative method will be central to this, with text coded and compared for similarities and differences until substantive categories emerge (Seale 1999). Explanations will be developed into which all the data fit, ensuring that deviant cases are also incorporated into the analysis. The qualitative data package NVivo will be used to facilitate this process. Interview transcripts will be written electronically and entered into the computer package (NVivo) as well as interview transcripts. By using NVivo the data can be coded and retrieved

enabling a comprehensive analysis of data including word searches, counts of phenomena and the identification of deviant cases (Silverman 2001).

Interviews

Semi-structured interviews were used in this research, due to the population we were working with, we wanted to create an informal atmosphere so the discussion guide was followed loosely and adapted to each interview. A list of topic areas and questions that shaped the process of the interviews and it can be seen in Appendix 1.

In total, 22 interviews were conducted with carers of patients with a primary malignant brain tumour. The face to face interviews enabled us to establish more personal views, narratives, and experiences that might not otherwise have been covered in the presence of others.

Ethical Permission

Prior to the research teams entering the field, ethical permission for the project was gained from the National Research Ethics Service (NRES) and the University of Surrey Ethics Board.

Individual Consent

Once permission to interview had been gained, a second stage of individual consent was sought by the research team. The carers signed the information sheet allowing us to initially contact them to set up the interview. Then, at the beginning of the interview we sought consent again in accordance with ethical NRES and SRA (Social Research Association) guidelines.

We have not divulged the identity of the participants, nor the exact locations of where the research took place. We coded transcripts accordingly, and at no point are names or identifiers used. Furthermore, all transcriptions will be stored in accordance with the Data Protection Act 1998.

Appendix 3 Participants Information Sheet

PARTICIPANTS INFORMATION SHEET

You are being invited to take part in a research study. This sheet provides you with information about the study, and what it will involve. Please read this information carefully, before deciding whether or not you wish to take part.

What is the purpose of the Study?

The study is a joint initiative between the ***** and the University of Surrey. It seeks to explore the support and information needs of those informally caring for a dependent with a brain tumour. Carers' needs are frequently ignored, and the aim of this project is to identify both the physical and emotional support systems that would be useful to them whilst they care for their dependent.

Do I have to take part?

It is entirely up to you whether you take part or not. If you do, you will be given this information sheet to keep and be asked to sign a consent form to show that you have agreed to take part. However, you will still be free to withdraw at any time without giving a reason. A decision to withdraw or a decision not to take part will not in any way affect the standard of care that your dependent receives.

What will be required of you?

The study involves taking part in a one-on-one interview that will last between 45 minutes and one hour. The interview will cover issues such as how well supported you feel in your caring role, and what additional aspects of support would be useful to you. A total of 25 carers are being asked to take part. The interview will take place in a location of your choice, agreed between you and the interviewer. This could include your own home, the hospital where your dependent is receiving treatment, or a neutral public space, such as a café or library. Any travel expenses you incur will be reimbursed. With your agreement, your interview will be tape recorded. However, any information that you give will be treated in the strictest confidence, and will not be linked to your name or personal details in any way. The interview material will be stored and destroyed in accordance with the Data Protection Act 1998.

What are the possible benefits of taking part?

We cannot promise that taking part in the study will help you, but the information that we get is likely to help carers in the future. The end result of this research will be the production of a booklet and website aimed specifically at providing carers like you with an information resource of where they can go for

their practical and emotional support needs. You will also receive a personal feedback report on the initial findings of the research.

Contact Details

If you would like to discuss any of the information provided here further please feel free to contact the Researchers at the University of Surrey Dr Anne Arber (Tel: xxx) and Nicky Hutson (Tel: xxx). Alternatively, please speak to the Specialist Clinical Nurse Douglas Guerrero (Tel: xxxx) for further information.

Taking Part in the Research

If you would like to take part in this valuable research, please complete your details below, and return the tear off below to the Specialist Clinical Nurse Douglas Guerrero. Dr. Anne Arber or Nicky Hutson from the University of Surrey will then contact you to answer any queries, and if you are happy to proceed, arrange a suitable time for the interview to take place.

Thank you very much for taking the time to read this Information Sheet.

ISN: 1

Name: _____

Tel: _____

Mobile: _____

Email: _____

Address: _____

Please * your preferred method of contact.

Signature: _____

Signature of Referring Clinical Specialist Nurse: _____

in conjunction with Consultant

Appendix 4 Consent Form

Carer Id number:

Study number:

CONSENT FORM

Project title: Exploring the Needs of Carers

Name(s) of researchers: Dr Anne Arber and Nicky Hutson, University of Surrey

Description of research project:

1. Participants are being asked to take part in an interview which will last between 45 minutes and one hour. This interview will be recorded and transcribed.
2. The transcriptions of the interview will be coded and kept at the University of Surrey and will be stored and destroyed in accordance with the Data Protection Act 1998
3. Only the researchers on this project will have access to this material.

I have been given information about the research project and the way in which my contribution to the project will be used.

Please tick the boxes below.

- I confirm that I have read and understand the Information Sheet dated for the above study, I have had the opportunity to consider the information, ask questions, and have had these answered satisfactorily.

- I understand that my participation in the study is voluntary and that I am free to withdraw at any time, without giving any reason, without my dependent's medical care or legal rights being affected.

- I understand that the information I provide during my interview will be looked at by the Research team at the University of Surrey.

- I agree to take part in the above study

- I give my permission for the information I am about to give/have given to be used *anonymously* for research purposes only (including research publications and reports)

- I hereby assign the copyright in my contribution to the researchers for research purposes only.

Signed Respondent.....Date.....

Signed Researcher..... Date.....

This information will be retained separately and securely from the information given during the process of the research.