WHICH PHILOSOPHICAL APPROACH PROVIDES THE BEST FOUNDATION FOR THE ETHICS OF DEMENTIA CARE?

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DECLARATION

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SUMMARY

Due to the increasing prevalence of dementia, caring for people with the condition is a global cause for concern. Ethics is an essential part of providing good care. However, ethics applied to dementia care needs to take account of the loss of cognition that results from the condition. There are particular challenges which arise when caring for a human being who has lived a normal life, but in whose current state does not fully resemble the person they were.

This thesis aims to establish which philosophical approach provides the best foundation for an ethics of dementia care that can be both inclusive of everyone with dementia and meet these everyday challenges. In order to do this, the methodological approach of philosophical inquiry has been taken. As such, the concepts and arguments employed in the philosophical and empirical work have been critically examined. The results of this inquiry have then been utilised to construct a new pluralistic ethical model.

The central argument of the thesis is that ethical approaches based on the moral status of the care recipient are not adequate and therefore should not be the primary focus for dementia care ethics. Instead, it is argued that a more promising approach is to embrace a virtue of receptivity (as advocated by Slote) in order that people are more responsive to the thoughts and feelings of those in their care. The ethical model proposed then combines this with principles to guide the care provider; as well as recognising the essential element of a supportive sociopolitical environment for the provision of ethical care.

To implement this change, a suggested programme for ethics education is outlined. Future research will consider both the success of the model and this education programme.

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ACKNOWLEDGEMENTS

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I would like to thank my supervisors Professor Ann Gallagher and Professor Terry Desombre, who have enabled me to find a way through the myriad of challenges that this process has presented.

Special thanks also go to Rt. Revd. Dr. Christopher Herbert and to Dr. Kathy Curtis whose comments on my work in its final stages were crucial to its successful completion.

The writing of this thesis has only been possible due to the generosity of others, not least my own family, to whom I am grateful.
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Dementia raises many questions about the human condition. It disrupts cognition, challenges personal identity and with that puts at risk the existence of elements that many of us consider fundamental to life’s value. Dementia care is therefore a challenging and special task. It needs to support people through periods of cognitive decline, while also nurturing the many positive aspects of human existence that arguably remain. To be inclusive, the ethics of dementia care must take account of the realities of people’s changing cognitive state.

I first became interested in the effect that the loss of cognition has on autonomy and personhood as a Masters student at the Department of Philosophy, University of York. At this point, I had worked as a mental health nurse for six years and it occurred to me that the way that health care problems are discussed in Philosophy is very different to how they are approached by those from a nursing background. In particular, there is a tendency to describe the situation of human beings who are deemed to no longer meet the criteria of personhood in a reductionist and non-emotional manner, which I found unsettling. I envisaged that doing ethics in this way would probably not be satisfactory to other nurses and care providers. There is a need to be respectful of the experience of the people whom our decisions affect, and latterly I have concluded, a need to be more emotionally involved too.

My Masters dissertation (Mitchell 2008) investigated how changes in cognition affect personal identity and the subsequent challenges that result for advance directives based in precedent autonomy. I argued that if respecting autonomy matters, then a social

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1 The term care provider is used throughout this thesis to represent anyone who provides care for someone with dementia, whether professionally involved or not. The term caregiver and carer have been avoided as these can be synonymous with non-professional carers in the literature. The term care receiver has been used for someone who receives care. The decision has been taken not to hyphenate these terms.
narrative view of personal identity provides the best chance of autonomy linked to this personal identity surviving the loss of cognition which results from dementia.

However, my argument rested on a number of assumptions. Firstly, the survival of someone’s personal identity and the autonomous wish to carry on a former way of life makes sense for someone who has a *temporary* loss of full cognition such as with an acute psychotic episode. Here people can be assumed to have an interest in picking up a life with its autonomously held beliefs and preferences. However, for the personal identity argument to work for people with dementia, it relies on the assumption that it matters in a *social* sense that the current life lived by the individual is continued in a manner consistent with their life narrative as whole. However, it is possible that those around the current individual would not value this. More importantly, it is possible that the current individual with dementia might show different (non-autonomous) preferences. As such, the current individual may end up being held to ransom by previous autonomous preferences about how their future self with dementia should live. All of these remarks also rely on the assumption that respecting autonomy is of prime importance.

These doubts led me to wish to explore the topic of autonomy and personhood in more detail. This formed the proposal for my PhD thesis. I presented this to the International Centre for Nursing Ethics at the University of Surrey, which has since become the International Care Ethics Observatory (ICE). After initial discussion, it became clear that it would be necessary to focus solely on dementia care ethics and to investigate what an adequate ethics in this area requires more broadly, beyond the autonomy and personhood question.

In order to do this, a range of philosophical approaches have been analysed. During the research process, I reflected on the uncomfortable feeling I experienced in the seminar room during my Masters degree. Early in the research process, I was sceptical about the value of emotional responses, wishing instead to focus on my project as a rationalistic endeavour. At this time, I was greatly influenced by the moral philosophy of Immanuel Kant and hoped that it would be possible to have a form of Kantian autonomy that would be inclusive of people with dementia. However, the arguments ultimately led back to a position sympathetic to this emotive starting point.
During my research, I have also continued to work as registered nurse, in practice with people who have severe dementia. This has been a further source of reflection. As the ethical model has taken shape, I have considered how it might apply in the situations that I face. Furthermore, being in practice has helped me to keep a grounded perspective and it has given me the opportunity to have discussions with many people who have been touched by dementia in various ways.

The aim of the thesis is to determine which philosophical approach provides the best foundation for the ethics of dementia care and to utilise the conclusions of this inquiry to construct a new ethical model.

The ethical model produced aims to be broadly applicable to anyone who is involved in dementia care. As such, it is of potential interest to professionals, people with dementia and their families. It seeks to offer a new way of thinking about the ethics of dementia care that will improve the lives of both people with dementia and those who support them. Dementia touches a large number of people in society so there is potentially a broader benefit in developing thinking about how society as a whole should relate to people with the condition. Furthermore, it is hoped the ethical model might signal the development of health care ethics in a direction that makes it more inclusive overall.

Chapter 1 will outline the significance of dementia as a global challenge. It will consider the physical changes that take place in the brain and the philosophical implications of dementia being a condition which is both progressive and permanent. The discussion will then consider the main challenges that an ethics of dementia care needs to respond to. The prominent ethical issues are outlined before going on to discuss the methodological and epistemological approach that the thesis is going to take.

Chapter 2 marks the beginning of an examination of philosophical approaches that might ground a new ethical model. Standard ethical thinking may not always be applicable due to the effect which the various conditions that cause dementia have on people’s cognition. Chapter 2 will consider if the concept of autonomy can be understood in a way that is both achievable for people with dementia while being rigorous enough to ground personhood as a moral status. The philosophical controversy surrounding issues such as personal identity and advance directives will be discussed in this chapter.
Chapter 3 broadens the discussion of personhood to examine whether it is possible to rethink the conceptual basis of personhood for people with dementia in a way that does not rely on autonomy. It will consider the ethical responses that might be entailed by the psychological properties held by people with dementia. It outlines the effect of setting the threshold of cognition needed to support personhood at different levels and the possibility that personhood may admit to different degrees. The discussion will then move on to the role of embodiment and whether it is possible for personhood to be linked to a shared human nature.

This leads on to the discussion in Chapter 4 which investigates building an ethical model around the concept of the dignity of humanity. It will examine the multifarious concept of dignity as both a subjective and objective notion along with its relationship to autonomy. The latter part of the chapter will evaluate whether humanness might be act as a source of intuitive understanding that can guide care. In order to investigate the source of this, an existential approach will be drawn on.

Chapter 5 will consider how the inner life of the care provider is relevant to the caring relationship. It will explore the notion of vulnerability in more depth before moving on to how this might guide a care provider in terms of cultivating virtues. The importance of empathy in caring will be examined, before introducing the key notion of receptivity. The role of moral education and exemplars will also be discussed.

Chapter 6 will examine the ethics of care and compare this philosophy to virtue ethics already discussed. This chapter will evaluate the argument for mutuality in caring which proposes that society at large values care as a sociopolitical concept. It will also examine the broad nature of decision making in the ethics of care and the importance of context and negotiation.

Chapter 7 will examine ethical approaches which balance principles and interests, and assess whether these approaches might be compatible with the ethics of care and virtue ethics approaches already discussed. The influential four principles framework of Beauchamp and Childress (2013) will be explored here, along with the ethical framework for dementia from the Nuffield Council on Bioethics (2009a). The notion of best interests will be examined before moving the discussion on to the role that consequentialism and contractualism might play in an ethical model.
Chapter 8 will draw together the philosophical arguments used to devise the ethical model. The model itself will be explained. Further worked examples of how the model might be applied will be outlined before moving onto how the model might be communicated as part of an ethics education programme.

The final chapter will outline recommendations that flow from the philosophical arguments before an overall conclusion is drawn.
1 THE MAIN CHALLENGES FOR DEMENTIA CARE ETHICS

1.1 INTRODUCTION

This chapter begins by outlining the significant nature of dementia and its prevalence, both in the UK and worldwide. There follows a description of the physical changes that various types of dementia cause in the brain and the decline in cognition that results. Dementia, unlike some other conditions which disrupt cognition, is progressive and permanent. The philosophical implications of this will be explored.

In order to construct an ethical model that is both relevant and workable in practice, it is necessary to consider the main challenges that the ethics of dementia care needs to respond to. This required a literature search of empirical and argument-based literature to be carried out and the results of this will be summarised.

One significant result of this initial search was the decision to focus on the everyday ethical issues that care providers face. The decision was also taken at this point to create a model that can be used not just by professional groups but by anyone who provides care for someone with dementia. This makes the ethical model more broadly useful and puts it the line with key legislation and the existing ethical framework produced by Nuffield Council on Bioethics (2009a).

The final section examines the methodology and epistemology that will be used in order to explore the philosophical approaches that might provide the best foundation for the ethics of dementia care.

1.2 THE DISTINCTIVE NATURE OF DEMENTIA

Due to its prevalence in society, dementia matters to an increasing number of people. Data obtained using a Delphi consensus methodology estimated that 1 in 88 people had dementia in the UK population in 2005, rising to over 1 in 9 by age 80-84 and over 1 in 4 by 90-94 (Knapp & Prince 2007). Prevalence was expected to rise with 1,735,087 people expected to have dementia in the UK by 2051, an increase of 154% from 2005 (Knapp & Prince 2007). Internationally, an increase of 234% was expected from 2001-2040 leaving 81 million people affected (Ferri et al 2005).
More recent studies have suggested that these initial calculations might have been inaccurate as the prevalence of dementia was significantly lower in the UK than originally predicted (Banerjee 2013; Matthews et al 2013). Newer data suggest that an improvement in lifestyle factors, such as smoking cessation, has reduced the amount of people who would otherwise have developed the condition.

Nonetheless, Banerjee (2013: 1835) adds a note of caution by stating:

‘Even with a small decrease in incidence and prevalence, population ageing will still double the numbers with dementia worldwide in the next generation.’

In line with this, the latest estimates are that 46.8 million people are living with dementia worldwide in 2015 and that this will increase sharply reaching 74.7 million in 2030 and 131.5 million by 2050. This is mainly due to a large increase in the prevalence of the condition in low and middle income countries (Prince et al 2015).

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Dementia can be defined as a progressive decline in cognition caused by a physical deterioration of the brain resulting in reduced social or occupational functioning. Along with memory loss, people may also experience language deterioration, poor judgement and impairment in visuospatial skills (McFerran & Martin 2014; Stephan & Brayne 2008).

The nature of this deterioration depends on the cause of dementia, such as Alzheimer’s Disease or Vascular Dementia (Nuffield Council 2009a; Stephan & Brayne 2008). Brumback (2004) describes the extent of the changes to the brain caused by Alzheimer’s disease, the most common condition that causes dementia. Initially, it causes damage to the limbic lobe of the brain, which results in the difficulty with memory found in earlier stages. It then progresses onto the temporal lobe producing problems with language use and comprehension. Next the condition moves to the parietal lobe which affects orientation to space and the ability to manipulate objects. Importantly, this can also result in ‘...problems with recognition of self and/or the environment.’ (Brumback 2004: 33).

Alzheimer’s disease then affects the frontal lobe, which involves loss of judgement and planning for the future, as well as the ability to interact socially. In the final stages, the
sensorimotor cortex and visual cortex are damaged resulting in ‘...the individual becoming immobile and relatively unresponsive.’ (Brumback 2004: 35). Brumback points out that the extent of deterioration is individual and non-uniform. For some people certain talents are reported to be preserved such as being able to play a musical instrument even in the end-stages.

Similar effects are found with other conditions that cause dementia. For example, posterior cortical atrophy causes a deterioration of the parietal, occipital, and occipitotemporal regions leading to progressive decline in visual and perceptual skills, literacy, and coordination (Crutch et al 2012). Vascular dementia is caused by a lack of blood getting to specific parts of the brain. As a result, it has a number of different subtypes depending on which part of the brain has been affected. Furthermore, a mixed picture of vascular dementia and other causes is not uncommon (Román 2005; Stephan and Brayne 2008).

***

How to respond to people with dementia is a societal concern and reports suggest there are a number of areas where care needs to be improved (House of Lords 2014; Care Quality Commission 2014; Parliamentary and Health Service Ombudsman 2011).

The ethical response is profoundly influenced by the decline in cognition brought about by the brain changes described above. Dementia is distinct from a number of other situations where cognition is affected. Dementia is progressive and permanent and therefore differs from temporary causes of mental disturbance such delirium or psychosis. Significantly, the state the person was in before the mental decline will never be fully regained, although the cognitive deterioration may not be continuous or regular (Stephan & Brayne 2008).

People with dementia are usually older adults and this means that unlike the situation with very young children and people with severe learning difficulties, most people with dementia have had, in their past, the cognitive abilities expected of a normal adult. This means that people with dementia have made autonomous decisions which they may now not be able to understand. As the condition becomes more severe, increasingly poor episodic memory severely also affects the ability of individuals with dementia to be able to update how they conceptualise their self (Eustache et al 2013).
These issues produce a distinctive set of ethical challenges in dementia care. In order to better understand what the concrete ethical issues are in practice, a literature search has been carried out.

1.3 LITERATURE SEARCH

The aim of the literature search is to ascertain what the main ethical challenges are in dementia care. Initially, it was decided to locate empirical research studies and reports that have sought to highlight the main ethical issues in dementia care. For this the databases CINAHL, MEDLINE, AMED, BNI, PsycARTICLES and PsychINFO were used employing a protocol driven search strategy utilising the following search terms

( dementia or Alzheimer* ) and AB ( ethic* and care) and AB (research or study)

TI ( dementia or Alzheimer* ) and SU ethic* and AB care

TI ( dementia or Alzheimer* ) and AB ( ethic* and care )

Publications were only included if they discussed ethics in dementia care, included themes that were potentially relevant to those providing dementia care and did not refer merely to research ethics. Following this criteria 159 relevant titles were initially found.

Next, existing philosophical (conceptual) literature on themes relevant to the ethics of dementia care was searched. A different strategy was used due to the different academic nature of the material. The main resource used for this search was Google Scholar utilising themes such as personhood, autonomy, dignity, vulnerability and advance directives. This was enhanced by analysing reference lists and knowledge of literature from the author’s previous philosophical research in the area (Mitchell 2008).

However, as the thesis developed, it became apparent that the latter method was better suited to this inquiry for both philosophical and empirical studies. This method is referred to as a snowballing approach and is one which employs the judgement of the researcher to find relevant references in the process of critically engaging with the literature already obtained (Greenhalgh & Peacock 2005). As well as examining reference lists of existing papers; citation tracking (available from Google Scholar) can also be used in order to see more recent articles that have cited the current article being
examined. As with Greenhalgh & Peacock (2005), I found this method yielded a greater number of relevant results for both empirical and philosophical studies and, unlike the initial protocol driven approach, was able to adapt as different avenues were explored.

1.4 FINDINGS

Following engagement with the literature obtained by the snowballing method, the following themes emerged as important.

**Figure 1** - Themes from the combined philosophical and empirical literature search

<table>
<thead>
<tr>
<th>Themes from the combined philosophical and empirical literature search</th>
</tr>
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<tbody>
<tr>
<td>Abuse by care providers</td>
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<tr>
<td>Advance directives, including surrogate decision-making</td>
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<tr>
<td>Autonomy, relational autonomy and precedent autonomy</td>
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<tr>
<td>Diagnosis disclosure</td>
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<tr>
<td>Dignity</td>
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<tr>
<td>Embodiment</td>
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<tr>
<td>End-of-life care, including feeding</td>
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<tr>
<td>Ethical frameworks and theories</td>
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<tr>
<td>Family carers</td>
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<tr>
<td>Mental capacity and consent</td>
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<tr>
<td>Medical treatment, including covert administration</td>
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<tr>
<td>Personal identity</td>
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<tr>
<td>Personhood</td>
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<tr>
<td>Quality of life</td>
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<tr>
<td>Religion / spirituality</td>
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<tr>
<td>Restraint</td>
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<tr>
<td>Sexuality</td>
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<tr>
<td>Staff attitudes or perceptions</td>
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<tr>
<td>Truth telling</td>
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<tr>
<td>Wandering and surveillance</td>
</tr>
</tbody>
</table>

These results can be compared to the findings of other researchers who have examined the relevant themes for dementia care ethics. These are summarised in the table below.
**Figure 2** - Relevant themes for the ethics of dementia care from other sources

<table>
<thead>
<tr>
<th>Theme</th>
<th>Coding categories</th>
<th>Consultation for the Nuffield Council on Bioethics (2009a;b) report on ethical issues in dementia.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Diagnosis and medical indication</td>
<td>Advance directives</td>
<td>Advance care planning</td>
</tr>
<tr>
<td>Assessing patient decision-making competence</td>
<td>Behavioural issues</td>
<td>Assisted suicide and euthanasia</td>
</tr>
<tr>
<td>Information and disclosure including:</td>
<td>Decision-making</td>
<td>Use of assistive technologies</td>
</tr>
<tr>
<td>a. Respecting autonomy</td>
<td>Driving</td>
<td>Freedom of action and risk</td>
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<tr>
<td>b. Information giving</td>
<td>Drug treatment</td>
<td>Sexual relationships and sexual disinhibition</td>
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<tr>
<td>Decision-making and consent including:</td>
<td>End-of-life issues</td>
<td>Truth telling</td>
</tr>
<tr>
<td>c. Advance directives</td>
<td>Family</td>
<td>Restraint</td>
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<tr>
<td>d. Surrogate / best-interest decision-making</td>
<td>Feeding issues</td>
<td>Abuse by family and friends</td>
</tr>
<tr>
<td>Social and context-dependent aspects including:</td>
<td>Genetics</td>
<td></td>
</tr>
<tr>
<td>e. Caring for relatives</td>
<td>Informed consent</td>
<td></td>
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<tr>
<td>f. Caring for carers</td>
<td>Legal issues</td>
<td></td>
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<tr>
<td>g. Resource allocation</td>
<td>Planning issues</td>
<td></td>
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<tr>
<td>h. Risk to others</td>
<td>Professional care and ethics</td>
<td></td>
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<tr>
<td>Care process including</td>
<td>Quality of life</td>
<td></td>
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<tr>
<td>i. Carer attitudes</td>
<td>Research issues</td>
<td></td>
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<tr>
<td>j. Patient involvement</td>
<td>Resources</td>
<td></td>
</tr>
<tr>
<td>Special situations including:</td>
<td>Treatment issues</td>
<td></td>
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<tr>
<td>k. Benefits vs harms</td>
<td>Truth-telling</td>
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<tr>
<td>l. Covert medication</td>
<td>General/Other</td>
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<tr>
<td>m. Driving</td>
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<td>n. End-of-life care</td>
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<td>o. Genetic testing</td>
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<td>p. Use of GPS and other monitoring</td>
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<td>q. Prescription of antibiotics and antipsychotics</td>
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<td>r. Restraint</td>
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<tr>
<td>s. Sexual relationships</td>
<td></td>
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<tr>
<td>t. Suicidality</td>
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Streich et al (2013) carried out a systematic qualitative review of the literature in order to determine the full spectrum of ethical issues in clinical dementia care. The main themes are shown above (in figure 2) with some examples of the sub-themes found by the authors. Ten years earlier, Baldwin et al (2003) mapped the literature by analysing keyword classifications on ethics and dementia articles from 1980-2000. Figure 2 reproduces their list of the more common and enduring keyword classifications. Finally, the Nuffield Council on Bioethics (2009a; 2009b) explored a number of common ethical issues which had been highlighted in the consultation process for their report Dementia: Ethical issues. These are also listed above.

A number of prominent themes can be identified by the frequency they appear in the literature. These are the use of advance directives; truth-telling, including diagnosis disclosure; balancing freedom with risk, including restraint and the use of assistive technology, sexual relationships, end-of-life issues, and administration of medical treatment.

The themes generated by the searches shown in figure 2 are almost exclusively on concrete issues in dementia care rather than philosophical themes with the exception of autonomy which is mentioned by Strech et al (2013). This is in contrast to the themes generated by the combined philosophical and empirical literature search carried out here. On the other hand, a recent literature review of studies published on ethical issues experienced by healthcare workers in nursing homes did find that the clash of ethical principles such as autonomy and beneficence was the most frequently raised issue (Preshaw et al 2015). This review was not specific about cause of these clashes and it needs to be noted that the focus here was not on dementia care ethics in particular.

1.5 THE IMPORTANCE OF EVERYDAY ETHICS

Reflecting on the literature and reviews of the literature brought the realisation that the most useful focus for an ethical model for dementia care is everyday ethics as this reflects what actually concerns care providers in their day-to-day work (Brodtkorb et al 2015; Strech et al 2013; Bolmsjö et al 2006; Powers 2001; Hasselkus 1997). This can also be referred to as a microethical approach (Örulv & Nikku 2007). This enables the model to be useful to a wide range of care providers on a day-to-day basis.
Everyday ethics examines the ordinary day-to-day issues which arise in dementia care that may not immediately appear to be ethical as they do not involve major treatment decisions, large scale concerns such as health care rationing or matters of life and death. Raising awareness of the ethical nature of these day-to-day issues aims to encourage people to reflect on how to improve the care provided. As Powers (2000: 144) puts it ‘...discovering the ethical in the ordinary forces reflection on what is taken for granted in the details of individual situations.’ Dauwerse et al (2012) also found there is a need for appropriate support to help staff identify these more ordinary ethical issues in care and consider different responses.

As such, other areas highlighted by Baldwin et al (2003) such as genetic testing and research ethics will not be the primary consideration here. Neither will there be particular attention to issues of a good death, palliative care, or euthanasia; though, the ethical model aims to be broadly applicable to these situations and these topics will be discussed to some extent. The ethical model aims to be sensitive to context and therefore resource allocation though not considered in terms of macro decision-making, it is considered relevant in terms of the options that are reasonably available for the care provider providing everyday care.

1.6 EXAMPLES OF EVERYDAY ETHICAL ISSUES IN DEMENTIA CARE

1.6.1 AUTONOMY AND THE USE OF ADVANCE DIRECTIVES

Ethical challenges can arise when deciding whether to respect principles that have been long held by the person but now have been forgotten.

An example is when a life-long vegetarian with dementia asks for a meat at a meal, having forgotten his or her previous vegetarianism. To respect the commitment to vegetarianism is to respect a choice, made in autonomy, from the person in the past. However, the current individual has no memory of this choice and wishes to experience the pleasure of meat.

As Hope and McMillan (2011) point out a lot depends on the initial reasons for vegetarianism. It may have been that, in the past, s/he did not like the taste of meat or that he merely made a lifestyle choice. In this case, it seems more reasonable to yield to a current stated preference than if s/he was previously a vegetarian through religious
conviction or due to a moral objection to the consequences of meat production such as animal suffering. If the latter is the case, then there are arguments that suggest that past convictions such as these survive and should be respected despite being unknowable to the current individual (Dworkin 1993). However, other arguments suggest the current preferences still take precedence as the connection with the person in the past (who would have abhorred eating meat) is made tenuous by the current individual’s inability to remember that choice (Dresser 1986). This will be explored in depth in Chapter 2 (2.9.2)

Advance directives have been proposed as a formal way of enabling autonomous future decision-making for when such abilities might be lost. Advance directives offer a way for people to make a choice about the type and extent of intervention they would accept in the future if incapable of making that choice at the time (Capron 2009). They can consist of a written or oral statement by the person or involve appointing a proxy to make decisions after capacity has been lost. In the UK advance decisions, or proxy decision-makers appointed under a lasting power of attorney, usually have the power to refuse treatment for someone who lacks capacity (Department of Constitutional Affairs 2007). There is also a facility for advance statements to be taken into account where a person can express their future preferences, although these are not legally binding.

Although, an existing advance directive may make the past preference clearer, it does not resolve the ethical difficulty of whether to favour past or current principles/preferences. A well-known example in the literature is that of “Margo” as outlined by Ronald Dworkin (1993). Margo is a thoroughly contented woman with advanced dementia. Her existence consists of repeating the same drawing, listening to music and appearing to read random pages in a novel. Dworkin considers what would have happened if Margo had written an advance directive stating a wish not to receive life saving treatment or even to be painlessly killed if in such a state. Does past Margo, have the right to make a decision about the current Margo? Should (precedent) autonomy be understood as a principle so strong that it outweighs current Margo’s right to exist in an apparently contented condition? Would past Margo have made a different decision if she had been aware of the contented nature of her future self?
The answers to these questions hinge greatly on issues of personal identity, a number of which are metaphysical in nature. How this problem might be tackled will be returned to in more depth in Chapter 2 (2.9.3)

1.6.2 TRUTH-TELLING

Truth-telling is a common issue for both professional and family carers. As pointed out rather frankly by James et al (2006a: 801) in reference to professional dementia care ‘...it is evident that lying is pervasive within care settings’. In their exploratory study of staff in various elderly care settings in North East England and Eire, it was found that 98.2% of respondents stated that either they or a colleague had lied to someone with dementia.

For a number of scholars in the bioethical field, lying to people in care is a prima facie wrong (Schermer 2007), which reduces trust (O’Neill 2002a) and fails to the respect the person’s humanity (Korsgaard 1996). However, there are times when lying appears to present itself as a viable option for relieving distress. A recent consultation among stakeholders in dementia care (Nuffield Council on Bioethics 2009b) produced a range of responses from a position of a prohibition of lying on one end to positions of lying to promote wellbeing (for either the carers or people with dementia) on the other. Seemingly the question produces polarised positions.

Schermer (2007) provides some concrete examples. The first is where a woman with dementia bangs on the door of a locked ward begging to be let out to collect her long since grown-up children from school. It is found that telling her the truth makes the distress worse; whereas saying her children will not be out of school for an hour eases the distress. This is a lie that colludes with a false belief. However, this belief allows the woman peace and the ability to talk about her feelings for her children.

The second example involves a widower who keeps asking how his wife is and is inconsolable every time he is told that she has died. Considering the man’s inability to remember the information combined with the fact that he becomes highly distressed every time he is told, produces a seemingly compelling reason to tell a lie despite the prima facie prohibition. However, to tell a ‘white lie’ might be argued by some as being disrespectful to his personhood.
Hasselskus (1997) in her discussion of everyday ethics makes a helpful distinction that these ‘white lies’ fall into two major types. The first are those that fit into the current reality of the person with dementia; the second creates a different reality. Schermer does not explore this latter option. However, a situation could be imagined where the widower discussed above repeatedly remembers his wife is dead (rather than asking where she is) but can only be consoled by the same lie that she is out and will return soon. There may be a moral difference here as this is contradicting a known truth rather than colluding with a false belief.

These examples and the issue of truth telling will be returned to in more depth in later chapters (3.4.2; 5.4.2; 6.3.2)

1.6.3 UPHOLDING DIGNITY

Though dignity did not feature in the conclusions of the reviews outlined in figure 2, it was identified in the investigation carried out here as a key concept in a number of the studies found in both the empirical and conceptual literature.

For example, an ethical challenge arises when a current preference or a practice of care providers is considered undignified in the context of the context of the care receiver’s life as a whole. To illustrate this, Chapter 4 (4.6) will consider a professor who has a long and distinguished academic career behind her. Now in an advanced state of dementia, it appears that providing the professor with a doll to cuddle, which she believes is a baby, is effective at reducing her distress.

A dilemma arises as there is evidence to indicate that doll therapy can be effective in this way (James et al 2006b). However, as a therapeutic approach this raises concerns about infantilization, which arguably leads to the professor’s dignity being compromised. On the other hand, Andrew (2006:419) argues that doll therapy preserves dignity more than the alternative methods of managing agitation such as using chemical or physical restraint, and it also maintains dignity by providing an opportunity to ‘...give care rather than receive it.’

In order to decide a dignified way forward, much turns here on how the concept is defined. Is dignity something that can be enhanced as well as respected? What is/are the source/s of dignity for people with dementia? Does it lie in a broader conception of...
dignity as a human being; or is it more specifically about being a fully functioning person, perhaps having a certain status or being of good moral stature (Nordenfelt 2004)? A certain view of dignity may lead to an alternative action such as providing the professor with academic journals to read that she no longer recognises. This may well respect the dignity of a meritorious role and fit with a more adult view of behaviour but it could also result in distress for the professor in her current state. Nonetheless, it is still an example of pretending, and is therefore also ethically questionable.

Chapter 4 will critically examine the concept of dignity and assess whether it can be helpful in such dilemmas.

1.6.4 MEDICAL TREATMENT

The everyday act of administering medication can raise a number of ethical issues. First, being the appropriateness of using medication as a chemical restraint in order to reduce challenging behaviour. This is described as an ongoing ethical struggle for professionals as sometimes they feel that the risk to the client, themselves or other clients leaves them with no other acceptable option but to ‘take the edge off’ using medication (Hassellkus 1997: 646). This dilemma is sharpened by recent research that certain types of sedation using anti-psychotic medication can be of particular harm to people with dementia and may result in premature death (Banerjee 2009).

A second issue is covert administration of medication. A review of the literature from Haw and Stubbs (2010) found between 43-71% of nursing homes in the UK disguised medication in food or drink. Ethical and legal justification relies heavily on the notion of best interests (Hughes 2006; Haw and Stubbs 2010; National Institute for Clinical Excellence 2015). The care provider needs to judge whether the covert act, along with any harm caused by the medication itself, is outweighed by the benefits of taking the medication. Truth-telling and the balancing of goods is an issue here. There is deception as the individual does not know they are taking medication but there may also be lying if the care provider states explicitly that there is no medication mixed with food in order to get the person to take it. The care provider has to make a judgement that the overall good (beneficence) outweighs concerns about deception and non-consensual intervention. This issue will also be returned to in Chapter 8 (8.5.2)
Reducing the risk of harm is a consideration for those who care for people with dementia. However, this has to be considered along with a claim to freedom, such as a need for people with dementia to go for walk (known as “wandering”). Robinson et al (2007) carried out a systematic literature review followed by a focus group study of professionals and carers on this topic. This found that a key issue to balance was working out the acceptable level of risk that can be taken in allowing the benefits of free movement to people with dementia. For professionals this caused a conflict between a promotion of person-centred care and the physical benefits of wandering on the one side, with a concern to not only maintain acceptable safety but also to avoid accusations of negligence and litigation on the other. As Powers (2000) points out, this is often a matter of weighing competing goods, but along with others in the area, Powers falls short of offering clear guidance as to how these weights should be ascertained. This perhaps illustrates why Robinson et al (2007) found that carers judged professionals to be overprotective in their decision-making about risk, whereas professionals considered carers to be taking unacceptable risks in favour of freedom.

One way of managing risk associated with movement is to use surveillance technologies such as tagging, tracking devices and cameras. Niemeijer et al (2010) carried out a systematic literature of surveillance technologies in residential care and found the central themes were institutional aims (efficacy, managing risk and staff burden); care relation (duty of care vs. autonomy, substitution of care by technology, person-centred care) and resident concerns (freedom and consent, privacy, dignity and sigma). However, the reviewers found that the articles reviewed were not able to delineate the ethical concepts clearly. For example, dignity can be employed on both sides of the argument. It may be believed that wearing a tag for tracking is unacceptable from a human dignity perspective, as being human dictates a prohibition on such an intrusion. Alternatively, it may be that using technology respects dignity by allowing some freedom while preventing people from getting into undignified situations such as being outside while inappropriately dressed. The issue of surveillance will be returned in Chapter 8.

Another area where freedom is in tension with risk is the area of sexuality. This is becoming a focus of increasing attention in the literature as the benefits of sexual
intimacy for people with dementia is being recognised (Makimoto et al 2015). However, people with limited decision-making capacity are at risk of physical exploitation, so the freedom to engage in sexual activity needs to be balanced with this risk. Consent is a central notion here. However, this may not be easy to assess. Furthermore, current preferences may be in tension with past values and beliefs. This issue will also be returned to in Chapter 8 (8.5.3).

1.7 METHODOLOGY AND EPISODEMEOLOGY

This thesis is a philosophical inquiry. As such, it is primarily a critical examination of the ideas and arguments used in the philosophical and empirical work relating to the area. This analysis will then be used to construct an argument for an ethical model which is sufficiently rigorous to be defended against similar scrutiny from others. This differs from qualitative research as the emphasis in a philosophical enquiry is on the reasoning employed in defending the thesis, rather interpretation of the data itself (Pesut and Johnson 2008).

It is also the case that in healthcare ethics, it is necessary for philosophical conclusions to grounded in reality and be applicable to real situations (McCullough et al 2004). Such a move has resulted in the proposal for an empirical turn in bioethics reacting against the traditional top-down approach of applying ethical theories to individual situations (Borry et al 2005). It is recognised, even by those who are sceptical of such an empirical turn, that empirical research can inform normative reasoning (Hurst 2010). For example, such research can be of use for assessing the nature and frequency of certain ethical problems in the field, as well as people’s reactions to these problems. Nonetheless, data collection alone is not expected to provide answers to ethical problems.

The ethical model must aim to stand up to empirical as well as conceptual scrutiny, in the sense that it has to be both viable philosophically and workable in practice for care providers. To test empirically the usefulness of the ethical model is beyond the scope of this thesis but could be a direction for future research.

In its conceptual analysis, this thesis will draw on methods such as those outlined by McCullough et al (2004) for appraising the argument-based medical ethics literature.
They have observed that argument-based literature is often based on a number of appeals to ethical principles, general ethical theory, casuistry, reflective equilibrium, tradition and current practice standards and professional virtues. Appeals that are generally not considered acceptable in philosophical discourse include arguments merely based on expert or majority opinion, law, or facts. Such appeals will be evaluated when they appear. This involves an assessment of how terms have been defined, whether the concepts are clear and whether the argument put forward is consistent and coherent.

Nonetheless, a note of caution is required. The analysis has to be flexible enough to be applicable to the large range of different ethical traditions which are being explored in this thesis. For example, an assessment of whether an ethical theory can form consistent rules that are universally action-guiding is not going to be relevant to a virtue ethics or care ethics approach which does not itself accept the need for such an assessment. It is not always coherent to criticise a philosophical approach from the perspective of another. It has been necessary instead to try and get inside the conceptual mindset of the various approaches to assess their merits. It is for such reasons that an overall framework from which to assess the philosophical argument-based literature is not appropriate here.
2 AUTONOMOUS PERSONHOOD

2.1 INTRODUCTION

Personhood has been highlighted as a fundamental notion in dementia care (Kitwood 1997; Brooker 2004; Edvardsson et al 2008). Personhood also has a long history in bioethics more generally, but has been variously understood (Macklin 1983). Controversy continues to surround issues such as the relevant criteria for having personhood, if it can be a matter of degree and how we ought to respond to those who are found to be at its margins (Kittay 2005; Tooley 2012). This leads to uncertainty about what it means to recognise and respect personhood when caring for people with dementia.

In everyday speech, personhood can be used as a descriptive term referring to all, and only those, beings who are biologically human (DeGrazia 2005; Sapontzis 1981). However, for the purpose of this thesis, personhood is functioning as an evaluative term meaning that the bearer has a particular moral status (Sapontzis 1981). Personhood is initially defined here as the full moral standing that is associated with persons, bringing with it particular protections and entitlements (Jaworska 1999; Jaworska and Tannenbaum 2013). Respecting personhood is understood here in terms of recognition respect as proposed by Darwall (1977). This means recognising an authority based on a particular fact about the entity being considered.

This chapter will begin the exploration of personhood by outlining how it might be grounded by autonomy, using the term autonomous personhood to differentiate it from other forms (Christman 2015). The chapter will introduce an example from dementia care. It will then explore individual autonomy by first differentiating it from freedom and highlighting the importance of the capacity for reflection in this context (Dworkin 1988). The link between this and the law on mental capacity will be examined. This will then be contrasted with the view of principled autonomy that focuses on the moral content of autonomous choice (O’Neill 2002a).

As difficulties arise with these views, the latter part of the chapter will consider how they might be modified. The first possibility is precedent autonomy (Dworkin 1986), which seeks to ground the moral authority of advance directives. The legal position will
again be explored before moving on to problematising advance directives as a way of maintaining autonomy. The main challenge here is defending the notion of autonomous personhood continuing despite radical changes to the person's psychology and perhaps their identity. Responses to this challenge bring further views of autonomy, leading to the consideration of a narrative view of personal identity (DeGrazia 2005); exploring more social and relational forms of autonomy (Kuczewski 1994; Mackenzie and Stoljar 2000) and finally the approach of ‘actual autonomy’ (Agich 2003).

### 2.2 Autonomous Personhood

Respect for autonomous personhood is based on the proposed fact that the individual with dementia has autonomy. Respecting autonomous personhood requires the facilitation of autonomous choices. The nature of autonomous personhood is dependent on how autonomy itself is understood.

The link between autonomy and personhood can be found in classical philosophy. The Kantian philosophical view directly links the moral status of being a person with the possession of autonomy as a property of the will (Kant 1996a/1785). More generally, autonomy is understood to be a capacity for self-governance, which provides people with the opportunity to live life in a manner of their own choosing (Christman 2015).

In biomedical ethics, the influential work of Beauchamp and Childress (2013) argues that ‘respect for autonomy’ is one of four key principles of decision-making. For Beauchamp and Childress, a respect for autonomy requires that it is made possible for people to express their preferences for treatment and care and that these are followed unless compelling reasons exist not to do so. This includes providing people with a sufficient level of truthful information to make such choices along with an entitlement to refuse unwanted interventions.

Yet, autonomy is a broad and contested concept. As such, this description may be either an oversimplification or misrepresentation of autonomy. As the concept of autonomy is variously understood, this affects the nature of what constitutes an autonomous choice and therefore who can make such a choice. Inevitably, this affects how the choices of people with dementia are evaluated.
The following example is suggested as an everyday ethical challenge that will be returned to throughout the chapter. Although fictional, it is based on empirical work by Powers (2001: 334) which identifies the need to learn ‘the limits of intervention’ in everyday situations. It relates to a commonly expressed concern of care providers about how much freedom should be curtailed in the effort to promote the well-being of the individual with dementia, as well as balancing the interests of those around them.

The aim of this everyday example is to illustrate how varying the understanding of autonomy in such a situation can alter the treatment of someone with dementia and the resulting implications for autonomous personhood.

Consider a man with dementia (called Bill) who lives in a residential nursing home. Bill has always been an active man and when he first moved to the home he used to say that he would never want to stay in bed past midday.

However, recently, Bill’s dementia has progressed and for the last week, he has decided to stay in bed all day until the evening meal at 5pm. This is despite having had a seemingly adequate amount of sleep, and there being no signs of physical illness. The main concerns are that his health may start to deteriorate and that he is losing the benefit of interacting with other people in the home. Furthermore, Bill is unable to remember that this is the seventh morning that he has stayed in bed. Should Bill’s wish to stay in bed until 5pm be respected?

The care provider has a belief that it is right to respect autonomous personhood. Nonetheless, she also believes that Bill is unable to understand why it is in his best interests not to stay in bed. Based on this judgement, she decides to carry out a seemingly paternalistic action. Bill is persuaded to get out of bed and go into the dining room in time for lunch. This is done by telling him that the rules of the home state that he needs to vacate his room before lunchtime, even though no such rules exist.

The care provider uses her position of power to move Bill (or get him to move) perhaps with an assumption that autonomous personhood is absent, or at least eroded to a point where it is not worthy of respect. Yet, it could be argued that the mere fact that Bill has stated his preference will be sufficient for it to be seen as an autonomous choice. If autonomy is understood and respected in this way, then it follows that it is wrong to
coerce and deceive Bill to get him out of bed. His preference should be accepted regardless of whether reasons for getting out of bed appear compelling or not.

An adult person in a usual situation in society could be reasonably expected to have an entitlement to make a choice about staying in bed, along with accepting the associated consequences. Such a person would therefore be protected from being coerced or deceived. If autonomy is used as the foundation of personhood, then the judgement that Bill lacks autonomy has led to at least some protections and entitlements associated with personhood to fall away.

The situation is further complicated as the care provider might still seek to justify the action to move Bill based on a claim that it is exercising his autonomy in a different way. This is because an alternative view of autonomy is available that gives precedence to a preference of Bill's from his past (to get up promptly) even though Bill is no longer consciously aware of it. This justification could be stated in simple terms such as: “Bill would not have wanted to stay in bed all day.”

Alternatively, the care provider may see themselves as taking a broader perspective, where the requirements of autonomy are part of the broader social context of the home as whole. As such it is considered acceptable to override Bill's choice as it is at odds with this social view.

Finally, the care provider may take the more extreme view that they have a position of legitimate authority where protections and entitlements are able to be overridden, such as it is generally accepted that state authorities are allowed to use a threat of legally sanctioned force to coerce even fully autonomous persons in the best interests of society (Anderson 2014). Here the care provider is taking a view that the protections and entitlements of autonomous personhood even if they do exist are not applicable in this context.

As this example shows, varying the understanding of autonomy produces different results in terms of how autonomous personhood might be respected. This chapter will now explore these various understandings.
2.3 INDIVIDUAL AUTONOMY

Depending on how it is understood, achieving autonomy can be more or less demanding. When someone with dementia states a preference, it is possible that this wish and the associated action will not be considered autonomous by those around them, as illustrated by the example of Bill above. Bill may well have the ability to express a preference to stay in bed and carry that out by acting to stay put. However, although it is possible that Bill has the freedom to stay in bed it does not necessarily follow that Bill is exercising autonomy by doing so.

Freedom is understood here to mean a lack of constraint on choice, concurring with a sense of negative liberty suggested originally by Berlin (1969). In this sense, Bill could be allowed to do as he wishes; however, the aim is to find the best philosophical basis for an ethics for dementia care. Therefore, it is important this is seen in the context of a broader ethical theory or system. Does the mere fact that the choice is freely undertaken create an obligation for it to be accepted by others? John Stuart Mill (2010/1859) comes closest to suggesting this in the work On Liberty in which he argued for a limitation of the interference by the state on the freedom of the individual. Mill believed that persons should be free to make their own choices in order to develop individuality and character.

Such views have the advantage of allowing many more choices to be exercises of autonomy and therefore by implication choices to be accepted by those who wish to respect the autonomous personhood of others. However, Manson and O’Neill (2007: 20) worry that leaving things merely to a matter of free choice would lead to a policy where choices:

‘...however bizarre, however self-destructive, however offensive, however degrading – will be permissible, and restrictions on them will be unacceptable’

Although this quote is not discussing decision-making by people with dementia in particular, the concern that accepting all free choices could lead to bizarre, self-destructive, offensive or degrading behaviour is relevant. Some examples could be quoted: a free choice to walk naked into a communal area; a free choice to leave a place of safety while being unaware of the danger outside; a free choice not to eat, or to refuse life-sustaining medication. Empirical research by Robinson et al (2007), Bolmsjö et al...
(2006) and Powers (2001) demonstrates that balancing such freedoms with the risk of harm is a common concern of those providing care for people with dementia in various settings, as well as for people with dementia themselves. This finding is also reflected in a recent consultation work from the Nuffield Council on Bioethics (2009b) which included people with dementia and their care providers.

Manson and O’Neill (2007) argue that autonomy, if thought of as merely free choice, cannot be seen as fundamental to ethics. However, few would argue that autonomy understood in such a minimal way could perform such a function. Beauchamp and Childress’s (2013) view of autonomy shows some similarity with more minimal views of the concept. However, it does include the requirement that the choice must involve a substantial (though not full) understanding, as well as intentionality and voluntariness. They also construct an ethical framework where ‘respect for autonomy’ in this sense is not central as it can be overridden by other key principles, such as beneficence. So this would respond to Manson and O’Neill’s concern as restrictions on choice would be acceptable, although it would mean that autonomy understood in this way cannot be solely fundamental to an ethical model, which is the aim for this chapter.

Mill (2010/1859) also calls for some restrictions on conduct of the individual by saying that for freedom to be valuable, desires and impulses need to be owned by the person concerned, pursuing their own good while allowing others to do so too. Arguably, it is these conditions that make the choice autonomous. It does this by giving the choice a greater value or moral significance by associating it with an authentic wish from the will of the person. As Dworkin (1988:26) puts it:

‘What is valuable about autonomy is that the commitments and promises a person makes be ones he views as his, as part of the person he wants to be, so that he defines himself via those commitments.’

Dworkin (1988) argues for a version of individual autonomy based on Frankfurt’s (1971) division of desires. From this, Dworkin distinguishes that preferences can be of the first or second order. A first order preference is where a person has a desire and prefers this to available alternatives. A second order preference is where the person is able to reflect on this first order preference and decide whether the preference is one that itself is preferred. For example, a person may have a preference for coffee over water. However, for it to be a second-order preference, the person must be able to
reflect on the first order preference and decide whether they would prefer to prefer water or coffee.

Furthermore, Dworkin (1988) argues that the person exercising autonomy must engage in a process of reflection that is subject to procedural independence. This means that the person must be able to reflect in a way that is free from manipulation or coercive influences; here, the actual content of the choice is not important.

The notion of procedural independence has been further developed by Christman (2004) who concentrates on determining what the procedure needs to be independent from. He points out that the process of reflection must meet the requirement that the agent could realistically imagine choosing otherwise if aware of the alternative reasons behind their decision.

To illustrate procedural independence, the example of choosing between coffee and water can be returned to. The addictive properties of caffeine, found in the example of coffee mentioned above, is something that can affect procedural independence. If this factor was not taken into account when reflecting whether to drink it or not this addiction could affect the independence of the thinking procedure, and it is possible that autonomy will not be exercised when the coffee is consumed. In other words, the agent in this case needs to be aware of the influence of caffeine addiction on their choice but still prefer to allow the addiction to influence their preference for coffee.

It is important to highlight that Gerald Dworkin's is a capacity based view. So a particular choice a person makes such as drinking coffee or staying in bed may be judged non-autonomous yet the person may still remain capable of making that choice autonomously. The important thing for Dworkin is that the capacity to make the autonomous choice is present rather than focussing on the choice itself. This focuses respect onto persons rather the choice. Indeed, this capacity Dworkin sees as being ‘a characteristic of persons’ (1988: 15), which concurs with the current stance of autonomy being a necessary foundation for personhood.

When seeking consent from cognitively intact individuals, healthcare professionals may assume that such a reflective process is possible and hope that it has been enacted in order to justify the choice in terms of this more robust conception of individual autonomy. This reflection would have to consider the pros and cons of such a wish
leaving open the possibility of rejecting this first order preference based on a wider assessment of the preferred direction of one's life as a whole.

Returning to our example, Bill may be able to say: “I am not someone who usually stays in bed all day but today I am particularly tired.” This suggests a link between a qualitative personal identity and autonomy (DeGrazia 2005). Bill could draw on his identity as someone who does not stay in bed all day as a possible reason for rejecting his first order preference, yet still decide in this case that the first order preference to stay in bed stands due to being particularly tired.

However, for some people with dementia, concerns may be raised about such a reflective process being possible, as dementia, by definition, involves a deterioration of such cognitive abilities (Stephan & Brayne 2008). In the case of Bill, the justification for overriding his choice to stay in bed could be grounded in such a concern. To have the capability to exercise autonomous choice, as currently being considered, he would have to be able to reflect on the wish to stay in bed. If unable to do so then arguably the choice could be overridden without disregarding autonomy as a concept or principle.

2.4 THE CURRENT LEGAL FRAMEWORK FOR MENTAL CAPACITY

The legal notion of competence may be linked to the ethical view of autonomy. This is because there is a level of mental capacity required before a person can be considered legally competent to make a treatment or care decision in the similar way that mental capacity has so far been argued to be required for an exercise of autonomy.

If someone is considered competent to make the decision then it arguably follows from a respect for autonomous personhood that the decision is accepted as their own, along with an understanding that the person also takes responsibility for the consequences. However, whether the requirements of autonomy are also met will vary depending on how it is understood.

As with the example of Bill outlined above, the harder cases are where someone is making a decision that is considered contrary to his/her best interests. Yet this does not give care providers an immediate licence to overrule such decisions. In the law of England and Wales the Mental Capacity Act 2005 Section 1 (1) states firstly that:
‘A person must be assumed to have capacity unless it is established that they lack capacity.’

And Section 1(4)

‘A person is not to be treated as unable to make a decision merely because he makes an unwise decision.’

In environments where the Mental Capacity Act 2005 is applicable, there is therefore a legal expectation that people's capacity to make treatment and care decisions should be assessed if the person has an ‘...impairment of, or a disturbance in the functioning of, their mind or brain...’ such as a form of dementia (Department for Constitutional Affairs 2007: 44). The Code of Practice in describing who should assess capacity points out:

‘For most day-to-day decisions, this will be the person caring for them at the time the decision needs to be made’ (Department for Constitutional Affairs 2007: 53) [my emphasis].

So, any care provider can be expected to make an informal assessment of capacity on a day-to-day basis.

The assessment criteria for Mental Capacity Act 2005 Section 3 (1) state that someone is unable to make a particular decision if they are unable:

(a) to understand the information relevant to the decision,
(b) to retain that information,
(c) to use or weigh that information as part of the process of making the decision, or
(d) to communicate his decision (whether by talking, using sign language or any other means).

If the individual assessed cannot do any one of the above, then this provides evidence for the care provider to declare that (on the balance of probabilities) the individual lacks capacity to make a particular decision. This then permits, in the legal sense, the care provider to make the decision on behalf of the individual in their care as long as it can been shown to be in their best interests.

Yet, it is important to note here that in the law of England and Wales, a best interests decision has to be take account the person’s past and present wishes feelings and
beliefs. Section 4(6) of the Mental Capacity Act 2005 requires the decision-maker to consider

‘...so far as is reasonably ascertainable—

(a) the person’s past and present wishes and feelings (and, in particular, any relevant written statement made by him when he had capacity),

(b) the beliefs and values that would be likely to influence his decision if he had capacity, and

(c) the other factors that he would be likely to consider if he were able to do so. ’

This suggests a weighting towards autonomy rather than beneficence. It may well be that the person has had a long-standing belief about what they prefer that is not considered to be objectively in their best-interests by those around them. However, the Act suggests that it may still be in the person’s best interests to follow such a course of action, even if others do not believe it will maximise benefit for them. This weighting towards autonomy is somewhat in tension with more utilitarian definitions of best interests that state it is about ‘...acting so as to promote maximally the good of the individual’ (Buchanan and Brock 1990 : 88).

However, the amount it is weighted towards autonomy depends on how autonomy is defined. Much is made in the legal framework of decision-making capacity being both decision-specific and time-specific (Department of Constitutional Affairs 2007). It is reasonable to state that at a certain time someone may be able to make a decision about one aspect of their lives but not another. However, the argument made in this chapter so far suggests that the important factor for autonomous personhood is the capacity to evaluate a particular decision in the context of broader interests or commitments in one’s life, rather than merely the ability to make each decision itself. The person needs to be able to decide if and how the decision is relevant to this. If this capacity is lacking, then they are lacking autonomy (as currently understood) in the more general sense. This is a more stringent test than the law requires.

Individual autonomy in its less demanding forms may remain possible for longer and may also be less susceptible to such fluctuations. However, the ability to choose in a way that is meaningful based on a commitment to live life in a particular manner seems likely to be lost as dementia progresses, due to the complexity of the reasoning
involved. With this, the justification for paternalistic intervention against the expressed wishes of someone with dementia arguably is strengthened as autonomous personhood (as currently conceived) is either absent or eroded to a point where it is considered not worthy of respect.

2.5 PATERNALISM

Paternalistic acts seek to promote the welfare of persons regardless of their current wishes (Dworkin 1988). The capacity to exercise autonomy negates the justification for paternalistic acts (Dworkin 1988; Holroyd 2009). However, much turns here on how paternalism is defined. A key distinction is argued to be the difference between hard and soft paternalism (Feinberg 1986).

Soft paternalism is the view that acting against someone’s wishes is justified only when the individual concerned is unable to act in a voluntary way. Consider the example where a stranger is about to cross a damaged bridge. There is not time to communicate the danger and the person concerned appears unaware of it. Soft paternalism justifies stopping the stranger (Dworkin 2010). Hard paternalism, on the other hand, allows interference even with voluntary acts, if it is felt to that this is necessary to promote someone’s welfare (Dworkin 2010; Beauchamp and Childress 2013). So even if the person was aware that the bridge was damaged and choosing to cross it, a hard paternalist action would stop the person, whereas a soft paternalist would let them cross.

Soft paternalism understood in this way may be compatible with autonomy if the welfare being promoted by a paternalistic act seeks to promote an autonomous preference against someone’s involuntary action. However, this leads Feinberg (1986), to raise the question of whether soft paternalism understood in this sense is actually paternalism at all, as it merely becomes a way of facilitating autonomy.

Interestingly, hard paternalism, if understood as interfering with fully voluntary choices in someone’s best interest may also be compatible with autonomy, if the voluntary choices are considered not autonomous (Scoccia 2008). On the other hand, if hard paternalism is understood as promoting someone’s welfare in a manner that violates autonomy, such as with Beauchamp and Childress (2013), then it clearly lies outside of
an ethical model grounded solely on autonomous personhood. Nonetheless, even hard paternalistic acts that offend against a full account of autonomy can still find ethical justification in beneficence (Beauchamp and Childress 2013; Scoccia 2008). Therefore, these acts cannot be excluded as an ethical course of action when caring for people with dementia without further argument.

Lastly, there is an assumption that underlies the paternalistic approach, namely that someone can know what is best for someone else. In order to break this assumption down and justify a paternalistic act, it is necessary to draw on other ethical concepts outside of autonomy such as consequentialism or a virtue ethics approach. The way that autonomy is understood is also relevant. Relational forms of the concept are more allowing of others influencing how autonomous decisions are made (Mackenzie and Stoljar 2000). This will be considered later in the chapter (2.10).

2.6 PRINCIPLED AUTONOMY AND THE CAPACITY TO VALUE

Drawing on the philosophical heritage of the concept, O’Neill (2002a) makes a basic distinction between individual autonomy and principled autonomy. The former being derived originally from John Stuart Mill’s (2010/1859) view of liberty as outlined above; the latter from Immanuel Kant’s (1996b/1797; 1996a/1785) view of autonomy of the will, which requires thinking and acting on principles that all others could also think and act.

Principled autonomy incorporates a moral element into exercising autonomy. As described by O’Neill (2002a), autonomy in thinking or action is the attempt to think or act on principles on which all other rational beings could also think or act. Autonomy, in this strict Kantian sense, requires that people legislate rather than merely decide. As such, an individual’s choices and behaviour must aim to conform to principles that both derive from the individual him/herself but could also be followed by all (Johnson 2008). In short, autonomy requires reasoning that strives towards universally applicable principles.

On the face of it, this appears more cognitively challenging than individual autonomy and therefore less likely to be possible for people with severe dementia. This creates a problem, as on the related Kantian view of persons, people with dementia could be seen
as outside the moral community due to lacking this ability and therefore not entitled to full moral consideration. However, such an interpretation of Kant is disputed by Korsgaard (1996; 2004) who states that even people without the ability to reason well can still be considered rational beings under a Kantian conception and are therefore seen as persons with the protection and entitlements associated that status.

According to Korsgaard (1996) rational beings are merely those beings that can value ends in life, aside from instinct. Korsgaard (2004: 85) describes a Kantian understanding of rationality as being a form of self-consciousness which involves being ‘...conscious of the principles on which we are inclined to act.’ This is opposed to non-rational beings that just experience the inclination without a conscious awareness of it. So, although the choice may not fully meet the requirement of Kantian moral agency, the important element is the striving towards principled autonomy, which involves the ability to value aside from instinct.

Along these lines, Jaworska (1999) argues that autonomy is based on such a capacity to value and involves the formulation of principles to govern one’s actions. Jaworska claims that people with dementia have a basic capacity to value. She backs this up with an empirical claim that in reference to Alzheimer’s disease the area of the brain responsible for valuing is less severely affected than the parts responsible for memory. Jaworska infers from this that although people with this form of dementia may be unable to remember their life as a coherent whole, they may still be able to value by laying down principles for their conduct. Jaworska states that this ability means the person is capable of autonomy.

However, Jaworska (1999: 130) does concede that

‘...possessing the capacity to value does not guarantee that the person can exercise autonomy to a full degree. Full-blown autonomy involves not only acting on one’s own principles and convictions but also the ability to scrutinize these principles and revise them in light of critical evaluation, so that they are well articulated and robust’

So the problem of reflection returns. Though it leaves the question of whether a basic autonomy which falls short of ‘full-blown’ autonomy is sufficient to do the work needed of it here to ground autonomous personhood. This is possible. However, it seems
reasonable to suggest that an unscrutinised principle is less convincing and more likely to be overturned by paternalistic motives.

Returning to the main example, Bill may (currently) hold a principle that a man should be left to his devices as long as he is not harming anyone else. However, further scrutiny of this principle might reveal other concerns such as a need to be sensitive to the current culture of residents socialising as a community, Bill’s previous preference to get out of bed early, the impact on Bill’s health etc. A seeming inability by Bill to engage critically with the principle could lead to a belief that Bill’s unscrutinised principle is best overridden on this occasion. Furthermore, Jaworska (1999: 134) goes on to exclude people with ‘late stages’ of Alzheimer’s disease from the capacity to value and therefore from her understanding of autonomy altogether.

So, a basic and reduced form of principled autonomy may be possible but it appears vulnerable in similar ways to individual autonomy when the capacity for reflection is reduced. One thing that has become clear is that the opinions and actions of care providers are often pivotal. It is they who make judgements about capacity and they who are often in the position to promote or restrict actions.

### 2.7 THE DISTINCTION BETWEEN AUTONOMOUS DECISIONS AND ACTION

Dworkin conceives exercising autonomy as not merely the ability to reflect and alter preferences but also ‘...to make them effective in one’s actions’ (Dworkin 1988: 17). In other words, the person must be able to execute the preferred act in order to exercise autonomy. This distinction is picked up by Holroyd (2009) who points out that there is a significant difference between autonomous choice, agency and action.

So far the discussion has focussed more on autonomy as a capacity the individual has (or had at some point in time) to make autonomous choices. Autonomous choice is a mental act. Autonomous action, on the other hand, is the execution of that choice in the particular situation. It can be assumed that to be worthwhile, the choice needs to be executed by an associated action.

However, Dworkin’s view on action can be challenged. If Dworkin is understood to mean that the person has to be capable physically of carrying out the autonomous actions themselves in order for them to be capable of autonomy, then this seems
unnecessary stringent. After all, many of our choices require the cooperation of others in order to be realised in the material world. It seems fair to say that the value of autonomy lies in the associated action being carried out according to the direction of an autonomous ideal \textit{without} the necessary condition that the human with autonomy is the sole performer in the present moment of a physical action. Nonetheless, requiring such cooperation adds additional factors into the exercise of autonomy.

Figure 3 describes the factors that need to be considered if autonomy is to be exercised with the assistance of a care provider. If the individual with dementia is unable to carry out an autonomous \textit{action}, then this puts the care provider into a pivotal role as they are now required in order for autonomy to be exercised. This is also a powerful and responsible role and one for which an ethical model for dementia care can make a potentially crucial intervention in assisting with decision-making.
Figure 3 – Factors to consider when exercising autonomy with the assistance of a care provider

Figure 3 outlines that if it is not possible for someone with dementia to exercise autonomy themselves, then the first requirement is that a care provider is both present and personally adheres to the principle that it is right to respect autonomous personhood. Next the care provider needs to be reasonably certain how autonomy might be exercised in this particular situation. This highlights again the key point of this chapter that different answers are generated depending on how autonomy is conceived.
If the care provider is reasonably certain of the autonomous choice, then further steps on the flow chart can now be considered. Firstly, is it possible to facilitate the exercise of autonomy with the resources available? If so, the care provider may still believe that despite an exercise of autonomy being possible and autonomous personhood being worthy of respect there are more compelling reasons why autonomy ought not to be exercised in the current situation. As this involves acting against what has now been deemed a voluntary and autonomous choice, justification would have to be found outside of respect for autonomous personhood. However, if compelling reasons cannot be found then the care provider can choose to assist the care receiver in exercising their autonomous choice.

A key point is that this process highlights the *powerful* position in which the care provider finds themselves. It also demonstrates importance of the sociopolitical context both in terms of the potential position of power that the care provider finds themselves in but also in terms of resources available to support the decisions being made. These factors will be examined in Chapters 6 and 8.

Overall if autonomy cannot be exercised then an alternative ethical strategy has to be found. The aim of the remainder of the thesis is to explore the possibilities for this alternative strategy and ultimately to construct an ethical model based on the result of the analysis.

### 2.8 SUMMING UP STANDARD VIEWS OF AUTONOMY

The possibility of people exercising autonomy based on standard views of the concept has been explored.

It appears that individual autonomy in its robust and meaningful senses involves the capacity for reflection that is procedurally independent. This means that decisions are made according to deeper second-order preferences that matter in the context of one’s life overall. This capacity is quite demanding and is likely to be beyond the reach of at least some people with dementia. It can therefore be stated that autonomous personhood based in individual autonomy cannot solely meet the aim of grounding an ethical model for the care of everyone with dementia.
The discussion moved on to explore principled autonomy. However, this found that exercising principled autonomy also requires the individual to be capable of a reflective thinking procedure about the choices made, which becomes impossible if the individual with dementia’s mental capacity is sufficiently reduced. However, these views need not be fully dismissed for the following reasons.

Firstly, the possibility of a model that adapts for varying mental capacity isn’t being ruled out. In other words, autonomous personhood would be respected if present but an alternative basis would also be needed for those who are unable to think or act with autonomy. A related possibility is that autonomy will feature as a principle or value but not a fundamental one in grounding personhood.

Secondly, there are further views of autonomy that draw on these standard conceptions but are adapted to take into account those who might be excluded due to current cognitive decline. Collectively these are referred to here as modified views of autonomy and will be explored now.

2.9 PRECEDENT AUTONOMY AND ADVANCE DIRECTIVES

In the first section, it was suggested that even if someone with dementia was unable to make an autonomous decision due to cognitive decline, it might still be possible for autonomy to be exercised. A promising candidate to allow for this is the concept of precedent autonomy. The term was initially coined by Ronald Dworkin (1986) and refers to an autonomous choice of an individual from the past that remains applicable at the present time when the individual is no longer considered capable of choosing with autonomy.

There is also the closely related concept of prospective autonomy where autonomous choices are made in the present with the intention that they will remain applicable in the future, despite a loss of mental capacity. Which term is used depends on whether the perspective is taken from the time of the autonomous choice being made or at the time when the past is being examined for such a choice (Quante 1999). For dementia care, it is suggested that the former is more relevant as the discussion is about how to respond to people in the present with a reduced capacity for choice. Therefore, the perspective of precedent autonomy will be taken up for the discussion.
The first question facing a care provider wishing to facilitate the precedent autonomy of someone else is how can their autonomous wishes be known? One vehicle for this is to use an existing advance directive. From the point of view of the care provider, these directives have been made by people in the past in order to choose the type and extent of intervention the individual in care would accept now they are deemed incapable of making that choice for themselves (Capron 2009; Atkinson 2007). They can take a number of forms, such as a past declaration by the individual concerned (also known as a living will or instruction directive); the appointment of a lasting power of attorney (also known as a proxy directive) or a combination of both (Olick 2001).

2.9.1 THE LEGAL POSITION OF ADVANCE DIRECTIVES IN ENGLAND

English Law allows decisions to have been made in advance of a loss of mental capacity in either written or oral form using the provisions of the Mental Capacity Act 2005. The term advance directive, although in common use internationally, is not one used in the Act. Instead advance directives are divided into advance decisions to refuse treatment and advance statements (Department of Health 2015; Department for Constitutional Affairs 2007). Both of these forms of advance directing are relevant for advance decisions in dementia care.

In English law, existing advance decisions to refuse treatment that are valid and applicable have the same status as contemporary autonomous refusals of treatment from a legally competent adult (Department for Constitutional Affairs 2007; Johnston & Liddle 2007). In order for the advance directive to be applied the decision must be considered to be valid and applicable by those who are responsible for making the decision. It is also possible to have a lasting power of attorney where the individual concerned has appointed someone else to make decisions about their care and treatment. An exception to this is if the directive involves a refusal of life-sustaining treatment then the decision has to be in written form, signed and witnessed (Department for Constitutional Affairs 2007). It also worth noting that as with contemporary treatment decisions made by the person in care, these can still be overruled by the Mental Health Act 1983, under which people with dementia may be detained (Department of Health 2015).
In contrast, *advance statements* outline preferences for future care and treatment, rather than refusing specific treatments. These statements are more likely to relate to everyday *care* issues than advance decisions to refuse treatment. However, unlike advance decisions, they are not legally binding (Department for Constitutional Affairs 2007; Jankovic *et al* 2010). In terms of an ethical response, advance statements are just as relevant as the legally binding advance decisions. There is also a requirement in the Mental Capacity Act Code of Practice to use any existing advance statements when acting in someone’s best interests. Nonetheless, although such statements should be *taken into account* as part of an overall decision; there is no legal obligation to adhere to the choice or act on a request for a particular treatment (Department for Constitutional Affairs 2007).

This effectively means that power and moral responsibility remains firmly in the hands of the care provider/s in the case of implementing advance statements, as they are not binding in the same way as advance decisions. However, even with advance decisions, the judgement on validity and applicability lies with the care providers. On closer examination the criteria for validity and applicability are quite stringent, and as a result there is leeway for the relevant care providers (in this case usually healthcare professionals) to declare an advance decision inapplicable or invalid. Examples of factors that can make the decision inapplicable or invalid are:

- ‘the circumstances are different from those that may have been set out in the advance decision’
- ‘there are reasonable grounds for believing that there have been changes in circumstance, which would have affected the decision if the person had known about them at the time they made the advance decision.’
- ‘….there have been changes in the patient’s personal life… that might affect the validity of the advance decision.’ (Department for Constitutional Affairs 2007: 171)

Jones (2014:102) adds that a clinician would have to enquire about

- ‘any doubts that might exist about the patient’s mental capacity at the time when the purported advance decision was made
- the information that the patient received about the consequences of the decision
- the circumstances surrounding the making of the purported advance decision
the possible effect of undue influence on the patient’s decision; and

whether the purported advance decision is applicable to the proposed treat and
was in tented to apply in the circumstances that have arisen.’

So if the person in charge of treatment believes for any one of the many reasons
outlined above that the decision is not valid and applicable, a legal avenue is open to not
follow the directive. Instead a route, based on the individual’s best interests should be
taken, which must still consider the advance decision but does not require it is followed.

Advance refusals can be described as stronger advance directives than advance
statements (Atkinson 2007), however, as can be seen, they can both be trumped by a
best interest judgement under specified circumstances. Nonetheless, both advance
refusals and advance statements can provide evidence of the autonomous wishes of the
person before they lost the ability to choose autonomously. This at least opens up the
possibility of respecting autonomous personhood in the present by using these
expressions of autonomy from the past despite these legal hurdles.

2.9.2 PROBLEMATISING ADVANCE DIRECTIVES IN PRACTICE

Returning to an example from Chapter 1 (1.6.1), I will consider an advance statement
that outlines a previously stated wish of someone with dementia to only be allowed to
eat a vegetarian diet. This situation has been highlighted as one of concern to people in

Consider Doris, a woman with advanced dementia. For the last 50 years Doris
has been a vegetarian. This is due to a strongly held moral conviction against
using animals for food. After learning of her diagnosis of dementia, Doris had
written an advance statement stating that under no circumstances should she be
allowed to eat meat. The care providers in the residential care home where she
lives are aware of this statement and have believed it to be the right course of
action to follow Doris’ original wishes, even though none of them share her
moral convictions. Recently though, Doris has started to ask for lamb chops at
the main meal. Doris has no recollection of her previous stance; she does not
know what a vegetarian is and does not appear distressed by the idea of eating
animals. In fact, Doris is angry when denied food that everyone else can eat. As
denying Doris the lamb chops causes her distress, many of the people involved in
Doris’s care have now started to question whether they should continue to follow her original wishes.

The care providers are faced with a dilemma. Should the advance statement or Doris’s current wish to eat meat be followed? If it is believed that Doris can make a current autonomous choice, then the advance statement is not valid and the decision is seemingly straightforward. Doris has merely changed her mind and (leaving aside arguments for vegetarianism) there is no compelling reason why she should not eat meat. However, Doris’s inability to recollect her previous conviction or understand its significance offers strong evidence against this being an autonomous change of mind. So, there is an apparent conflict between Doris’s current wish to eat meat and her advance statement that states an autonomous wish to live a life free of meat eating.

If the care providers wish to respect the autonomous personhood of Doris, then there is a duty not to disregard a valid autonomous choice. After all, if Doris were able to autonomously refuse to eat meat in the present situation, it would be disrespectful to her autonomous personhood to coerce Doris to eat meat or be deceptive about its presence in her food for reasons outlined in the discussion on standard views of autonomy. Similarly, when Doris was competent in the past she may have had the same preference to taste the lamb but still remained vegetarian. This is because, as discussed, the value of autonomy lies in being able to override a first order preference in order to concur with the preferences or values a person has for their life as a whole.

So the key concern is whether it is reasonable to say that a past statement is an autonomous choice with the *same authority* as would be the case if Doris could make a contemporary autonomous choice. There is a case for this and, as discussed, the principle is supported by English law through advance refusals of medical treatment, which are legally binding.

Seemingly, less controversial examples of advance decision-making can be imagined. Someone signing a consent form before an operation would reasonably expect a surgeon to honour their autonomous wishes while unconscious. Someone who plans their funeral in detail could reasonably expect their autonomous wishes for the service to survive their bodily death, seeing the funeral as part of their life as a whole. In a similar way, people may express an autonomous wish for organ donation (Mitchell
2008; Quante 1999). Even so, it is important to note that a view such as that of Buchanan and Brock (1990) that these preferences are interests that survive incompetence, unconsciousness or death is not sufficient here. Recall that the aim of this chapter is to establish how autonomous personhood might form an ethical model for dementia care. Interests do not necessarily imply autonomy, autonomous interests or autonomous personhood. So, further work will need to be done to establish how autonomous personhood can ‘survive’ in dementia.

So, what are the relevant concerns when respecting Doris as an autonomous person? Firstly, the care providers have to be sure that Doris’s current preference for meat is not an exercise of autonomy after all. Recall that Jaworska (1999) argued that even when the capacity to decide is absent, the capacity to value may remain. So in Doris’s case, it may be that she has genuinely developed different values about meat eating which can erode the moral authority of the existing advance directive. However, recall that Jaworska (1999: 130) also argued that ‘full blown’ autonomy involves the ability to scrutinize such values. Doris’s inability to scrutinise her new values weakens its appeal as a direct opponent to her previously held moral convictions. The validity of using such a minimal expression of autonomy to overrule a previously robust stance is questionable.

Secondly, in line with the legal discussion above, there is the objection that advance statements or advance decisions to refuse treatment can be inaccurate and/or unreliable. For example, the content may not be articulated in a way that accurately reflects the wish of the person concerned; wishes may be misunderstood by the reader or misinterpreted by a proxy decision-maker; they may not be explicit about the treatment refused or the preferred care requirements; updates to wishes may not have been made, have got lost or been forgotten about (Dimond 2008; Holland 2003; Olick 2001). These practical concerns have to be attended to for any advance directive to be taken seriously. Dresser (1994) fears that these concerns create a serious, perhaps insurmountable, educational challenge for policymakers who wish to implement advance directives. However, Olick (2001) argues that many of the practical differences can be overcome by taking a common-sense view about the content of the directive rather than becoming overly preoccupied with its specificity.
Even if most of the practical difficulties can be resolved, some deeper problems remain. Again in line with the legal discussion, unreliability results when circumstances change that are not allowed for in the directive. An interesting proposal is raised by Nelson (2009) who considers what might happen if the foundation of one’s convictions change after the directive is written. Let’s suppose that Doris’s moral objection to meat eating is based on the teaching of a particular religious organisation. Let’s also say that the religious organisation on which Doris’s bases her conviction has recently changed its position, deciding that eating a moderate amount of meat is acceptable after all. This would cast serious doubt on whether Doris’s original conviction is still valid. Nelson suggests that the autonomous interests expressed in the advance statement would also shift with the change of doctrine from the organisation. However, there is considerable uncertainty here as it may be that a change in the perspective of the religious organisation would be enough to have occasioned Doris to leave or join a faction that still supports vegetarianism.

A related difficulty is that the author of an advance statement or decision to refuse treatment may be making a decision about a situation in the far future, about which they have insufficient knowledge. It is difficult to know what an experience of having dementia is going to be like.

This problem is brought into sharper relief by returning to the example of “Margo”, outlined in Chapter 1 (1.6.1). This example found in the work of Ronald Dworkin (1993) was in response to a personal experience of a medical student, Andrew Firlik (1991).

Recall that Margo was a woman with advanced dementia whose day-to-day existence consisted of repeating the same drawing, listening to music and appearing to read random pages in a novel. Despite this, Margo appeared very contented with her existence. Dworkin considers what might have happened in this situation if Margo had written an advance decision stating a wish not to receive life-saving treatment or even to be painlessly killed if in such a state. Should such a directive be followed, respecting Margo’s autonomous wish to prefer death to continued dementia, despite it appearing that Margo is living an enjoyable existence with dementia?
There are a number of ways that pressure can be put on a decision to follow the advance decision to refuse treatment. Firstly, it is impossible for a younger Margo to know for certain how the older Margo would feel in this state. However, it would be possible for the younger Margo to make a clear directive that states that even if she appears contented, she still wishes to be allowed to die, based on perhaps a perceived indignity of having dementia. It is worth noting again that such decision to refuse life-sustaining treatment in the event of dementia would be legally binding in English law as long as the specified conditions are met (Department of Constitutional Affairs 2007). This would be legally equivalent to a currently competent Margo refusing treatment.

Yet, if the motivation of Margo in writing the advance decision is to shorten her life with dementia by refusing life sustaining treatment, then a Kantian view of principled autonomy may question whether such an advance decision is actually an exercise of autonomy at all. Recall that such a view of autonomy considers that a choice can only be autonomous if it based on principles that all others can think and act (O’Neill 2002a). The question therefore needs to be asked whether a principle of shortening life due to a wish not to exist in a state of cognitive decline is one that can be rationally willed by all. If Margo’s directive is seen as equivalent to suicide, then such a principle would be disallowed by many Kantians as it cannot be willed as a moral act (without contradiction) that human persons destroy a human body that brings morality itself into the world (Kant 1996b/1797).

However, Velleman (2008) argues that hastening death is morally acceptable in Kantian terms when there is a deterioration of someone’s state to the point where their autonomy and its associated dignity become compromised. Yet, if it is decided that autonomous personhood has to be compromised to allow such an action, then it is no longer forming a basis on which to make decisions. This leads back to the same difficulty that the advance directive was initially trying to overcome.

It does remain possible that Margo without autonomous personhood has a claim to be kept alive by medical treatment. For example, it could be argued that the happiness produced by Margo remaining alive outweighs other considerations. However, this is not a subject for this section, the aim of which is to find a way that autonomous personhood can ground an ethical model.
2.9.3 THE PERSONAL IDENTITY CHALLENGE TO ADVANCE DIRECTIVES

Even if the practical and moral objections of the advance decision are able to be overcome, there remains a serious worry about the moral authority of such a directive from the past applying to Margo in her current state. The challenge is now based on the notion that the advance directive lacks authority, as the individual is not sufficiently psychologically connected to the person who wrote the directive to be considered the same individual (Dresser 1986).

This challenge is based on metaphysical ideas about what is required for personal identity and in particular what is needed for us to be the same person. In common parlance it may be said that Margo is not the person she used to be. However, the claim here is Margo may actually not be the same individual. The reason that Margo is still called by the same name and is legally the same person is due the fact that Margo is a continuation of the same biological organism.

Yet, the radical change in Margo’s psychology leads to a concern that Margo is not the same person as she was before. Support for this idea can be found in the work of Derek Parfit (1984). He argues that what matters to us is not that we can identify with the same human body through time but that have psychological continuity that he describes as being formed from ‘overlapping chains’ of strong psychological connectedness (Parfit 1984: 206). These connections consist of memories as well as other psychological factors such as commitments, character or beliefs. These connections vary in their strength. This means that psychological continuity, although in its logic is all or nothing, is actually in its nature a matter of degree (Parfit 1973).

The key point here is that in the case of Margo, Doris, or anyone with similarly severe dementia, there is a reduction in psychological continuity to the point where the individual with dementia is no longer a continuation of the autonomous person who made the advance decision or statement in any sense that matters in terms of carrying out its content. So it follows that the interests that may have mattered to Margo if she had completed an advance decision to refuse treatment are no longer applicable to Margo with dementia as there is not sufficient continuity of psychology.

If a view of personal identity is taken that is based on such psychological continuity, then Margo with dementia would not be the same person who wrote the directive.
(DeGrazia 1999). If the psychological view of identity is then combined with a view of autonomy that is based on psychological or mental capabilities, then this results in a no-win situation for autonomous personhood. In order for an advance directive to apply, there is a perceived reduction of mental capabilities, resulting in an inability to make autonomous choices in the current situation. The aim of turning to advance directives was to respect autonomous personhood by allowing autonomous decisions from the past to now be applied. However, it now appears that this same reduction in mental capability that brings the advance directive into force can result in a disruption to psychological continuity meaning that the autonomous decisions from the past and the personhood to which it is associated are no longer applicable after all. Therefore, either way autonomous personhood is absent.

Yet, Ronald Dworkin (1993) in his description of the problem argued that if an advance decision had been made by Margo then it should have been applicable to Margo in a state of dementia. Dworkin (1993) argues this by making a distinction between experiential and critical interests. Our critical interests represent critical judgements relating to our life as a whole and are somehow more deeply held, whereas experiential interests are more transient interests that we have in enjoying experiences. We have critical interests in our life proceeding in a certain way that fits with what we believe is important for us. If we wish for our life to be coherent as a whole, we may choose to forgo a certain pleasurable experience as this is not part of our long-term plan.

As described above, choosing with individual autonomy also involves making decisions that are based on a wider assessment of the preferred direction of one’s life as whole. Critical interests can therefore be aligned with the exercise of more demanding forms of individual autonomy and therefore aligned with autonomous personhood. Dworkin (1986) calls this an integrity view of autonomy. This view focuses on people having a coherent plan rather than having reliable evidence of one’s best interests. It therefore neatly dismisses the concern that making an autonomous decision would require evidence of what having dementia might be like.

Nevertheless, with cognitive deterioration, the ability to choose with autonomy is lost and critical interests formulated in the past can no longer be known by the individual who possesses them. Crucially though, Dworkin argues these critical interests do
remain. So, the potential conflict of interest is not between the different psychological selves: Margo with dementia and the past competent Margo. For Dworkin, the conflict is within Margo with dementia, though she is unaware of it. If Margo had directed that the last chapter of her life should go in a certain way, and we wish to respect Margo’s autonomous personhood, then her critical interests, even in her demented state, should prevail. The advance directive should be respected.

2.9.4 NARRATIVE VIEW OF PERSONAL IDENTITY

This move can be achieved by relying on a narrative view of personal identity, rather than a psychological view. The narrative view looks at personal identity in a different way. It sees the question of who we are as being most important aspect of personal identity (DeGrazia 2005). People can decide what is important to them and from this create their identity (at least to a certain extent). Narrative identity is the qualitative part of personal identity. This is in contrast to numerical identity which looks at essential properties that keep objects the same and forms the basis of the personal identity challenge from the psychological view (Holland 2003). Yet, DeGrazia argues that narrative personal identity still needs a form of numerical identity in order that the narrative can be identified to a particular human being. Importantly, though, DeGrazia argues that the numerical identity required here is biological not psychological. In other words, narrative identity presupposes the continuing existence of the human body (called Margo) rather any psychological criteria.

So this result suggests that Margo before dementia owned her body and this gives a right to decide on its care and treatment which continues even though it is now inhabited by Margo with a radically different psychology (Furberg 2012). If the advance directive is honoured, this leaves Margo with dementia in the seemingly unfortunate (yet for her unknowable) position of inheriting a body over which nobody is able to have a current say about its continued existence, as its last chapter has already been written.

The same arguments now can be applied to Doris and the vegetarian dilemma. If Dworkin’s arguments are accepted, then Doris is also in a position where she no longer has full control over her body. Following the advance statement means that Doris is refused the freedom to eat meat due to her past moral convictions that she can no
longer understand. Doris’s last chapter is one in which she remains vegetarian and due to her inability to author a viable alternative, this is how it will have to stay.

However, Dresser (1995) raises an objection to the notion of narrative coherence behind Dworkin’s integrity view of autonomy. In particular, she questions the empirical assumption that people actually have or want to have a coherent life plan as proposed by Dworkin, suggesting instead that ‘...many people take life one day at a time’ (Dresser 1995: 36). Moreover, she puts forward that people may want a ‘surprise’ ending to their lives.

This criticism drills deeply into the value of autonomy in general. If Dresser’s criticism is accepted, then it challenges the idea proposed earlier that autonomous choice requires reflection based on the second-order preferences that matter in the context of one’s life overall. Taking each day at a time would make it hard to commit to such preferences and perhaps would suggest that autonomy would have to be understood in a more minimal sense. However, paradoxically taking one day at a time could be seen as a higher order preference in itself. To have such a view could produce an advance statement stating a wish to have one’s contemporaneous wishes taken more seriously than one’s autonomous past preferences. This line of reasoning would suggest that Dresser’s objection is not fatal after all.

A deeper worry is whether it is reasonable to identify (numerically) with the continuing human body rather than its psychology, when it is the psychology of the person that matters in the sense that the content of the directive is an expression of an autonomous will. In other words, as it is psychology that matters how can the continuing body be relevant?

A plausible response to this is that the person’s narrative and their autonomous wishes, survive in the psychology of others who identify them with the continuing human body. So the conflict is not within the current individual as was suggested with Margo earlier; it is between the past autonomous wishes expressed in the advance directive that now live through others and the individual’s current non-autonomous preferences. Does the survival of an individual’s autonomous wishes in the psychology of others mean that autonomous personhood is viable in a form that it can ground an ethical model? The next section will investigate this claim.
2.10 RELATIONAL AUTONOMY AND THE SOCIAL SELF

It is suggested by Kuczewski (1994) that autonomous interests, as expressed in an advance directive, can survive in the memory of others. Referring to how he would see himself in a future state of incompetence, Kuczewski (1994:42) states:

\[ \text{The body that belongs to the incompetent patient at } t_2 \text{ [a future time] is in some sense “mine” because other persons call it by my name and make the story of what happens to it a chapter of the story they tell about “me”. As such I attempt to make that chapter embody the values which are presently mine.} \]

This is an extension of the notion of an ownership right to the body discussed above. Here the ownership is justified by the fact that the community still sees the continuing human body as part of the narrative of the person who declared their autonomous preferences. Furthermore, Kuczewski (1994:42) has a conception of himself as part of a larger group that also contains ‘part’ of him, adding that his story is ‘…to some degree, only complete when told from this vantage point from outside of my stream of consciousness.’ This implies that our narrative identity as persons is formed at least partially by the people around us. As Christman (2004) points out, communitarian views such as this, along with feminist views of relational autonomy, put pressure on the standard (liberal) view of autonomy that focuses on an individualistic understanding of the self.

Importantly here, this opens up the possibility of autonomous personhood also being a social notion. Though, it needs to be made clear what is meant by this. Recall, that autonomous personhood is understood here as the moral status of persons. As a result, the notion being considered is this:

\[ \text{Can an ethical model be constructed based on the moral authority of a social form of autonomous personhood for individuals, which endures even when those individuals are no longer capable of autonomous choice themselves?} \]

The Nuffield Council on Bioethics (2009a: 117), in its report on ethical issues in dementia, leaves the reader in no doubt of the importance of a social and relational element in autonomous decision-making:
'We also argue that autonomy should be seen in ‘relational’ terms: that is, that a person’s sense of self and self-expression should be seen as being firmly grounded in their social and family networks.' [my emphasis]

Relational autonomy shares with communitarianism a conception of autonomy that emphasises the importance of social conditions, as a reaction to the traditional view of individual autonomy which is perceived to idealise ‘rugged’ individualism (Mackenzie & Stoljar 2000:5).

Some theorists such as Donchin (2000) take a strong view of relational autonomy, which states that autonomy by its very nature is a social concept. This would lead to the further conclusion here that autonomous personhood (as a moral status) is only possible through social means.

This emphasis on interdependence appears a promising route to support and include people with dementia. However, there is some ambiguity. Does society merely maintain an individual’s autonomous personhood when competence is lost, or is autonomous personhood something which is actually generated by social interaction allowing this process to carry on as long as a human being exists to take part in the tale? Kuczewski’s (1994) view appears to imply the latter. The view from the Nuffield Council (2009a), on the other hand, could mean either. If it is the case that society merely maintains an individual’s autonomous personhood, then it begs an explanation as to how an individual’s personhood can be maintained without other people generating that personhood from their own consciousness. Unless a satisfactory explanation for this can be found, it will have to be assumed that autonomous personhood is generated in some way by society (including family) around the person.

To help clarify the concept, Donchin (2000: 240) suggests that when conceptualising relational autonomy it is necessary ‘...to steer a path between two risks’.

The first risk that Donchin refers to is one that reflects the feminist lineage of relational autonomy. This is where the individual’s expression of autonomy does not take into account the social conditions enough and by doing this actually allows power imbalances in society to be ignored and therefore persist in the ‘guise’ of autonomous choice (Donchin 2000: 238). This highlights the overall concern of relational theorists that standard models of autonomy do not sufficiently account for the fact that people
can be vulnerable to such influences, and therefore people make decisions without being aware of the context that has led them to make that choice.

This view suggests that whether autonomy is exercised or not is highly dependent on an awareness of prevailing social conditions. It appears to imply that those who are oppressed by society are constrained from thinking autonomously. This gives the seemingly unwanted result that people who are in such a position of being oppressed would no longer have protection from paternalism, as it would be allowable for their arguably non-autonomous thinking to be dismissed (Holroyd 2009).

In weaker forms of the concept, this awareness of social conditions means simply appreciating one’s social context and reflecting on which of these values one should take as their own (Donchin 2000). However, this weak form cannot do the work needed as the aim here is for autonomous personhood to continue beyond a time when such reflective decision-making is possible. Therefore, it is necessary to understand relational autonomy in a stronger form.

Yet, stronger forms lead to a second risk, which is that a person’s individual self is overwhelmed by social considerations. Society may constitute autonomy to the point where the notion of self-government is effectively lost as the self and its narrative is subsumed. The ‘autonomy’ that remains here is not the authentically persevered wish of a past individual self; instead it is a reflection of the beliefs and interests of the social group to which the individual belongs. This appears to be a potential risk in the approach suggested by the Nuffield Council above.

It was not made fully clear above what is meant by Nuffield Council on Bioethics (2009) when they say that a person’s sense of self should be firmly grounded in social and family networks.

To elaborate, the Nuffield Council on Bioethics (2009a: 117) supposes that:

‘...most people [with dementia] would wish that their carer’s interests should be given considerable weight: their interests include their carers interests. When autonomy is understood in these terms, then in order to support a person’s autonomous wishes and values it will be necessary to support the whole family and social structure.’
Yet, this is open to challenge. The wording suggests an empirical claim that *most people* would see themselves sharing their autonomous interests in this way when in a state of dementia. Evidence needs to be offered before such a claim can be taken seriously, but even then the problem remains as to how to conceive autonomy for the minority who don’t have this wish. Moreover, it needs to be understood how the relational view fits with the Nuffield Council’s overall framework of autonomy and well-being interests.

The Nuffield Council on Bioethics argue that ‘autonomy interests’ are promoted by offering choice for people with dementia. Yet, they argue that weight is also given to autonomy interests by emotional responses. Arguably these autonomy interests conflate with well-being interests as well-being interests involve ‘a satisfaction of their [a person with dementia’s] desires and preferences’ (Nuffield Council on Bioethics 2009: 28).

From the discussion above, it further appears that autonomy interests also take account of the interests of carers and family members. It is therefore becoming hard to establish any interests at all that are not a kind of “autonomy interests” when this term is more broadly understood. This lack of demarcation makes it problematic to make a decision which respects autonomous personhood where autonomy is understood in a way that allows it to support interests that are so broad and potentially conflicting.

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In summary, it appears that if autonomous personhood is to continue despite incapacity using the social accounts such as from Kuczewski or the Nuffield Council then there are two plausible possibilities. The first is a more metaphysical claim (Christman 2004) that autonomous personhood results from a self *constituted* by the society (including family) around the person. The second is the claim that the society around the individual with dementia will choose to regenerate and respect their personhood by being faithful to the person’s narrative as best they can.

Yet, both of these are unreliable. The first because society may constitute autonomy to the point where the notion of self-government is effectively lost as the self and its narrative is subsumed by the beliefs and interests of the social group to which the individual belongs.
The second because it makes an assumption that society will want to continue the narrative of the person concerned, and further argument is needed as to why there is a moral reason in terms of respecting autonomous personhood for continuing this narrative. In other words, why ought people around the individual (without autonomy) be applying the autonomous wishes expressed from the past to the individual in the present? One possibility is to return to the argument from the previous section that it is the continuing ownership right over the body that provides moral authority (Furberg 2012). However, this fails to attend to the worry that motivated this current section; this being that the continuing human body is not what matters most, as it is psychologies (not bodies) that generate autonomous personhood. In short, many families and care providers may choose to maintain the narrative of the person but the grounding of this as respecting autonomous personhood of the current individual remains open to challenge.

Recall that in the example of Doris the care providers around her do not share her moral conviction against meat-eating. If these care providers are the only social network that remains then it seems possible that Doris’s narrative could end up being rewritten to reflect the new values of the situation in which Doris now expresses a contemporaneous preference for meat-eating. On the other hand, it also seems possible that the care providers may choose to go against the prevailing social conditions and declare that they are (as a social group) keeping Doris’s original values alive so that her last chapter is one where she is vegetarian. On the above views, it could be argued that either way this is respecting autonomous personhood in a social sense.

Yet, perhaps this more flexible view of autonomy is exactly what is required for autonomous personhood to survive as a notion that includes people with advanced dementia. This leads to the final view of autonomy to be considered, the phenomenologically derived account of “actual” autonomy.

2.11 ACTUAL AUTONOMY AND PARENTALISM

In opposition to idealistic (liberal) forms of autonomy, Agich (2003) proposes the concept of actual autonomy that appeals to a practical understanding of the concept that is relevant to everyday experience. From this, Agich (2003: 1) aims to develop an ethical framework that is able to include the long-term care of older people who have a
reduced ability to ‘function independently’ or ‘choose rationally’. As described by Agich (2003: 11)

'The framework involves a developmentally orientated and phenomenologically derived account of the ordinary or everyday sense of autonomy in terms of concrete human action in the shared world of social life.' [my emphasis]

A number of themes are raised here that are worth exploring in more detail. Firstly, Agich believes that it is necessary to take a developmental perspective to understand how autonomy is actualised in practical situations in everyday life. Importantly for Agich, this involves taking a phenomenological view, which he contrasts with communitarianism. Although, he agrees with communitarians that a social view is necessary to counteract overly individualistic forms of autonomy, he criticises the concept for stating that the social aims of community can overwhelm personal autonomy, in a similar way to feminist social views discussed above. In meeting this criticism, Agich (2003: 126) proposes the alternative phenomenological claim that ‘...sociality is an essential feature of being a person’, meaning that to be a person requires the tendency to develop social ties. So rather than society somehow subsuming individual autonomy, as is arguably the case with communitarianism, Agich describes how being an autonomous person necessarily involves social ties. He hopes that this claim about the everyday nature of the social world from our concrete experience provides a framework that gives meaning to personal autonomy.

The more flexible view of autonomy that appears to be required for people with dementia can therefore find its grounding in the diverse reality of everyday existence rather than in an ideal theoretical justification. This emphasis on sociality means that human beings can only exercise autonomy on this view through supportive human relationships; in short, it links dependency with autonomy. This results in a view that keeps the communitarian view of people as social interdependent beings, whilst hoping to also maintain the agency of the individual.

As part of this view, Agich (2003:48) endorses the concept of parentalism, which is a form of ‘...autonomy-respecting paternalism’. The suggestion is that far from the forms of paternalism that are juxtaposed to autonomy, parentalism does not seek to cause dependence in the individual being cared for, nor does it intend to impose a best interests view over a ‘competent’ choice. A similar view is expressed by Donchin
(2001:381) who is sympathetic to an ‘optimal parenting relationship’ as part of a relational understanding of autonomy in health care.

Yet, this raises the objection that an attitude of parentalism, though acceptable towards children, is not acceptable for adults. Can parentalism manage to side-step the objections made against paternalism? Agich himself states that it shares with soft paternalism the justifying of ‘... actions undertaken against unreasonable or incompetent decision-making.’ (Agich 2003: 49). If this argument is accepted, it appears that a care provider can override a choice of someone that they consider unreasonable, yet still be respecting their autonomous personhood in actual terms. Agich goes on to question whether paternalism is as compelling a practical concern in everyday life as it is in theory. Nonetheless, a conception of autonomy broad enough to sanction others to carry out seemingly paternalistic acts (deemed more reasonable or competent than the individual’s preference) is highly sensitive to the prevailing social conditions.

A second difficulty is the understanding of personhood (in the general sense) that emerges. Agich’s view suggests that personhood consists of being an interdependent agent (Hughes 2005). Yet, what this means for the moral status of autonomous personhood being examined here is harder to decipher. This may be because the question of what moral status results from being autonomous is not one that a phenomenological theory of autonomy seeks to answer. Instead, it seeks to understand autonomy in a descriptive way rather than seeking a theory of autonomy that can make normative judgements.

As a result, applying “actual” autonomy to the example of Doris does not appear to move the discussion any further forward. The care providers may wish to take a parental or autonomy-respecting paternalistic approach; however, it seems that this could involve either responding to Doris’s contemporaneous preference for meat-eating in a meat-eating environment, or keeping Doris’s original values alive. Nor does Agich’s theory offer any guidance for the well-rehearsed example of Margo from the contemporary literature, discussed above. Agich, although sympathetic to a narrative approach to understanding personal identity does not engage with the dilemma that this appears to create.
Similarly, if we return to the original example of Bill, the phenomenological view that sees him as an interdependent agent in his everyday world may well be accurate as a description. However, this *on its own* does not offer clear guidance as to whether it is therefore allowable to use the social conditions of a care home, Bill's health and his previously stated position that he is “not someone who usually stays in bed all day” as sound reasons to persuade him out of bed. There is a good chance that such a broad and flexible view of autonomy can lead to equivocal judgements casting significant doubt over its ability as a concept to constitute autonomous personhood as a foundation of an ethical model.

Actual autonomy promotes the notion of personhood being broadly conceived in a similar manner to the influential figure of Tom Kitwood; although, puzzlingly, Agich himself does not discuss this comparable work (Hughes 2005). Overall, actual autonomy is far enough from autonomy's usual theoretical and normative pedigree for further discussion of its guiding phenomenological themes to be returned to in later chapters.

### 2.12 Evaluating Autonomy as a Source of Personhood for People with Dementia

The aim of this chapter was to establish if autonomy can be formulated in a way which allows it to be possible for people with dementia yet robust enough to ground a reasonable claim to personhood. As dementia involves a reduction of cognition, a primary consideration was to deduce which views of autonomy might remain viable for people with more severe dementia.

Firstly, standard views of autonomy were examined. These were broadly divided into forms that require a moral element in autonomous choice (principled autonomy) and those that see autonomy as a capability without reference to the content of the choice (individual autonomy). Ultimately, this division was not crucial. It was found that both individual and principled autonomy can be understood in ways which make them more or less inclusive.
In order to include the largest possible number of people with dementia, less stringent versions of autonomy as an expression of free choice or a basic capacity to value can be advanced. However, decisions made in this way are open to challenge from others.

Instead, it was argued that for all standard views, autonomous thinking needs to include the ability to reflect on immediate preferences in terms of broader values as this approach provides a strong claim for the moral status of autonomous personhood. This ensures that the resulting choices are judged on an equal ground with those of other persons and there is a prima facie prohibition against the will of others being routinely imposed in the form of paternalism. Yet, this approach means excluding from autonomous personhood those people who are incapable of this reflective thinking procedure, leaving people with more severe dementia without the status of autonomous personhood.

This conclusion moved the discussion on to consider whether it is possible to modify these standard views of autonomy in order to make them more inclusive of people with severe dementia. A promising avenue for modifying a standard approach to autonomy is the concept of precedent autonomy. This underpins advance directives and is commonly used in health care systems. This is where someone’s autonomous choice from the past remains applicable at the present time when the individual is deemed to no longer be able to make the autonomous choice. In their English legal form, advance directives are only binding when they take the form of an advance decision to refuse treatment and only then when considered valid, applicable and not overruled by other legal means such as by the Mental Health Act 1983. Though, in terms of an ethical model, all advance statements outlining preferences are ethically relevant as expressions of autonomous will, even if they vary in their legal force.

On exploration, the concept of advance directives as a vehicle for autonomous personhood proved problematic. Firstly, practical problems can make directives an unreliable way of understanding someone’s autonomous will. Also, there are potential difficulties with some choices being seen as not meeting the moral requirements of principled autonomy. However, the greater challenge comes from the notion that advance directives lack authority as the individual is not sufficiently psychologically connected to the person who wrote the directive.
In order to maintain the identity of the person despite psychological disruption, a narrative view of personal identity has been suggested. For the purpose of this chapter this required autonomous personhood to also be engendered by such a narrative. On further investigation such a narrative view relied heavily on a biological view of personal identity stating that a person’s autonomous narrative maintains authority essentially because it is associated with the same human body. This is problematic as the ground of the original challenge was that it is the psychology of the person that matters, in the sense that is crucial for the content of the directive.

A plausible response to this was to investigate whether the person’s autonomous narrative somehow survives in the psychology of others who identify it with the continuing human body. This view finds its reflection in communitarianism and relational autonomy. More specifically it suggests two possibilities. Firstly, autonomous personhood results from a metaphysical constitution of a social rather than individual self. Secondly, the alternative idea is that people will choose to regenerate and respect someone’s personhood by being faithful to their narrative (or being true to their memory).

Both of these proved unreliable. The first because society may constitute autonomy to the point where the self and its narrative is overwhelmed, meaning that any notion of self-government is effectively lost. The second because it makes an empirical assumption that society will want to continue the narrative of the person concerned, and further argument is needed as to why there might be a moral reason for this.

This suggests that despite over 25 years of discussion in the literature, the problem of the moral authority of advance directives remains unresolved.

Finally, the approach of actual autonomy was examined. Here advance directives are no longer relevant as the aim is to find a way of describing autonomy that is relevant to people in the current situation of physical and/or psychological dependence. In many ways this approach is the interdependent, social view of autonomy writ large. However, the framework is descriptive rather than theoretical and does not seek to make normative judgements. The only concrete guidance offered is to adopt an approach of parentalism, which effectively allows a degree of soft paternalism. Arguably this is stretching autonomy to a point where it is losing its basic character of protecting people
from such paternalistic acts. Furthermore, “actual” autonomy does not offer enough to ground autonomous personhood in the harder cases. Its phenomenological form does not lend itself to such a project and, moreover, if attempts are made to apply it in such examples, it suffers the same objections as other social approaches of producing equivocal results.

This chapter began by highlighting that controversy surrounds how to treat those at the margins of personhood. It was hoped that the concept of autonomy could form an approach to personhood that could attend to this problem. However, this has not been fully successful. The possibility remains that an ethical model might adapt for varying mental capacity. People with sufficient mental capabilities would be able to draw on the protections and entitlements of autonomous personhood, with an alternative ethical route for those with lesser cognition. Alternatively, autonomy could feature as a principle or value that is not fundamental to personhood but still relevant to the ethical model as a whole.

Overall, it has been argued that autonomous personhood does not meet the aim here of being a fully inclusive concept on which to ground an ethical model. Nonetheless, personhood is broad concept that does not necessarily rely on autonomy.
3 PERSONHOOD NOT GROUNDED BY AUTONOMY

3.1 INTRODUCTION

Personhood has been defined as the full moral status or standing which is associated with persons (Jaworska 1999), bringing with it particular protections and entitlements. However, this leaves the question open as to what constitutes a person.

The previous chapter investigated how personhood might find its grounding in autonomy, variously understood. Though not dismissed altogether, it was argued that autonomy was not sufficiently robust to ground personhood for everyone with dementia. The current chapter will broaden the investigation further to consider how personhood might otherwise be realised.

This broadening brings about a somewhat different approach. Rather than having an ethical notion (autonomy) as a starting point, a number of factors relevant to personhood that are either held by, or associated with people with dementia will be investigated. However, these factors or attributes must enable the necessary philosophical work to be done by showing how the moral status of personhood has been engendered by it. Furthermore, it will then be necessary to show how personhood, once engendered, might provide a foundation for an ethical model for dementia care.

A set of factors commonly thought to meet these requirements to ground personhood are psychological capacities. In classical philosophy, John Locke (1979/1700: 335) states that a person is:

‘...is a thinking intelligent being, that has reason and reflection and can consider itself as itself, the same thinking thing in different times and places...’

In contemporary times this Lockean understanding has been developed by David Parfit (1984), who advanced the notion that persons consist (merely) of chains of psychological connectedness containing memories, beliefs and desires and it is the continuing existence of this psychology that matters to us.

The first section of this chapter will consider the ethical responses that might be entailed by various psychological properties. Then the investigation will consider which of these psychological properties are held by people with dementia and how they might
be relevant to personhood. Setting the threshold of cognition to support personhood low enough to be inclusive of all people with dementia brings implications and these will be explored. The possibility of having degrees of personhood will also be considered.

The discussion will then explore the relevance of embodiment in the debate. It will ask if the body can provide at least a partial basis for personhood in this evaluative sense. An influential contribution here is the Situated Embodied Agent (SEA) view of Hughes (2011a; 2008; 2001a) that draws on the philosophical heritage of Heidegger and Merleau-Ponty. Here the idea is that personhood is derived from an intimate combination of the physical body, its contextual situation and its psychology. The argument states that the continuation of the living human body situated in context is a necessary part of personhood. From this it is possible to ascertain a level of agency, even with severe cognitive deficit, as people understand other human beings instinctively due to ‘our shared nature’ (Hughes 2008: 129). This view will be evaluated before moving to a conclusion.

3.2 PSYCHOLOGICAL VIEWS OF PERSONHOOD

Psychological properties offer a strongly intuitive candidate for the foundation of personhood. To demonstrate the importance of psychological properties, Tooley (2012) draws on previous philosophical work in the area. He asks the reader to imagine having their psychology entirely erased, whilst their body survives supported by lower brain function. Plausibly, he proposes that the intuition people experience in this situation is that they would have lost something supremely valuable even though their body survives.

The prohibition on murder reflects how society sees the destruction of the living body along with its psychology. However, this intuition suggests that personhood is the status held by the psychology rather than by the body, making the destruction of someone’s psychology on its own similarly wrong.

To further illustrate, Tooley (2012) then asks the reader to consider how having one’s psychology replaced with pseudo-memories, beliefs, desires etc. might affect the intuition. The remaining individual has the same living human body and is
psychologically normal. From an objective perspective, there is still a human person in the world. Yet, from a subjective point of view this may appear to be the same as death. This is because from the point of view of the subject, it will no longer be *him/her* in the body. He/she will be unable to recall the past or express the same hopes for the future. As a result, it is likely that this action, if possible, would also be seen as murder.

There are parallels here to the view of Derek Parfit (1984) mentioned above; though, Parfit takes the reductionist psychological view one step further by dismissing the separateness of persons and the importance of personal identity altogether (Glover 1988). In other words, for Parfit, it is the maintaining of psychological connections not any identity associated with it that matters. Nonetheless, these views all agree that people have an interest in the survival of cherished psychological connections, whether associated with an identity or not.

Although not responding to Tooley's case directly, DeGrazia (2005) challenges the intuition that underpins the psychological view. He states that someone in the position of being about to experience serious physical pain (by torture) is consoled neither by the prospect of having *his/her* entire psychology erased nor by having it replaced. DeGrazia (2005: 26) suggests this reaction:

“Great,” you think sarcastically, “massive amnesia followed by torture.” When you hear that, in addition to losing your memories, you will acquire what seem to be memories of someone else’s life, this seems even worse: “Madness followed by torture.”

Yet, this opposing intuition seems to rest on a mistake. It appears to assume that there will be some of the original psychology remaining after the erasing or reprogramming. Otherwise there would be none of the original psychology to produce the thought after the erasing event “I now have amnesia and I am still going to be tortured” or “I now have someone else’s past.” If there was no original psychology, then this experience would not be possible. On the other hand, if there is some of the original psychology left that is able to understand that the past is forgotten or replaced with someone else’s then the psychology is still connected in a way to the original in order to be able to make that assessment of loss. This might only be a minimal flow of experience to link the present and past moment (Dainton 2014) but this would still suggest a form of
psychological continuity. Although in a much reduced psychological state, this suggests a continuing self-consciousness.

If the amnesia proposal means that someone’s episodic memory (the memory of their autobiographical events) is completely erased, then it arguable that the total lack of a past would actually make it impossible to have a stream of consciousness at all in the present (Gennaro 1996).

Looking at the situation impersonally, the pain will still be felt and this is a bad outcome. However, if erasing or reprogramming occurs to the extent proposed by Tooley’s cases some relief might be felt that it will not be you who will feel the pain. Nonetheless, this consolation is somewhat empty as it would result in your current consciousness being annihilated.

At this stage, DeGrazia’s response appears unconvincing. The discussion will consider further arguments for the role of embodiment later. At this stage, however, it will be assumed that the psychological view holds and as such it is our continuing psychological life that we value. In the case of most human beings these psychological properties are seen to be of sufficient value to provide the moral status of personhood.

3.3 PRIMA FACIE DUTIES RESULTING FROM PERSONHOOD

The status of personhood associated with these psychological connections provides protections and entitlements too; though, these vary depending on the ethical theory being employed. A classical deontological view is that persons have absolute worth and therefore can never be treated merely as a means to achieve someone else’s end (Kant 1996a/1785). In Kant’s terminology this is derived from the absolute worth of Humanity in persons, by which Kant means a special capability to set ends and rationally pursue them. (Johnson 2008). This provides a prohibition on destruction of the person through murder or suicide but also generates other duties such as a prohibition on lying.

On the other hand, for a utilitarian perspective the focus is on consequences. It sees persons as having special capabilities, such as being able to reflect on their situation and have hopes for the future. So if persons are thwarted in some way, or they have knowledge of soon being so, then they are going to suffer more than other beings
making this action more harmful and therefore “more” wrong (Singer 2011). This view based on an equal consideration of interests will be returned to in Chapter 7 (7.3).

The current section of this thesis examines the former view that personhood provides certain deontic constraints on what behaviour is acceptable towards someone who is a person. Yet taking such a strategy can lead to some seemingly absurd consequences related to absolute positions. A common example being Kant’s argument that we must be truthful in all statements and this duty cannot be overridden, even if this results in another person’s death (Kant 1996c/1797). A further example is where an innocent person is prohibited from being tortured, even if this torture is the only way to prevent a large number of other innocent people’s deaths. This second example is more controversial yet still many people would be inclined to override the prohibition of torture in such a circumstance.

As a result, it appears that in more extreme circumstances there is a move away from absolute prohibitions in favour of consequentialist concerns. Although once the move away from absolutism has been made, new problems arise. For example, it is far from clear what the right answer is to the question of how many innocent deaths would have to result before a prohibition on torture ought to be lifted (Alexander and Moore 2012).

Nevertheless, it seems reasonable to conclude that to be applicable an ethical model would have to avoid seemingly absurd conclusions. So it is apt to proceed with the notion that the status of personhood is of very great but not absolute value. This means that the rights that come with personhood and any correlated duties are prima facie.

Based on the work of WD Ross (Ross 1930), to have a prima facie duty means that there is a feature of the act that gives us a moral reason to carry it out. For example, we may have a prima facie duty to respect a person by not deceiving them. Yet, there could be other features that provide conflicting prima facie duties. In Kant’s example a conflicting prima facie duty would be not to act in a way that puts someone else in mortal danger. As Ross (1930: 28) puts it:

‘Any act that we do contains various elements in virtue of which it falls under various categories. In virtue of being the breaking of a promise, for instance, it tends to be wrong; in virtue of being an instance of relieving distress it tends to be right’
What we ought to do – our duty *proper* – is unambiguous yet hard to determine. Ross indicates that whatever it is, it involves the ‘whole nature’ of the act (Ross 1930: 28).

It is worth noting that WD Ross’s work has been credited by Beauchamp and Childress (2013) as being influential in their “four principles” approach. This will also be returned to when principlism is discussed in Chapter 7 (7.2.1). For our purposes here, Ross’s conclusions will initially be accepted in the context of the duties arising to those with personhood. This means that duties to persons are not absolute as the whole situation provokes a number of other competing reasons in the search for a right action.

Nonetheless, the key question remains: can personhood, so understood, be established for people with dementia?

### 3.4 Basing Personhood on Psychological Properties for People with Dementia

Establishing personhood based on psychological properties for people with dementia requires a search for the key psychological properties concerned. Returning to Tooley (2009: 33), it is suggested that the following factors may each be considered sufficient for personhood:

- Moral agency
- Capacity for rational thought
- Having a mental life that involves an adequate amount of psychological continuity and connectedness
- Self-consciousness
- Being a subject of non-momentary interests
- Simple consciousness

It needs to be determined which of these suggestions are plausible both in terms of their ability to ground personhood and whether these factors are possible for people with dementia.

### 3.4.1 Moral Agency, Rationality and Psychological Continuity

In the previous chapter, the notion of *moral agency* as a ground for personhood for people with dementia was considered in depth. Some people with milder dementia will
retain the ability to have moral agency. However, serious doubt has been cast on the capability of people with more advanced dementia to have such a capacity. For people in this situation, further options will need to be considered, if psychological capacities are going to ground personhood for those who have the condition.

**Capacity for rational thought** is worthy of consideration. If rationality is associated with the capability for *reflective* deliberation, meaning an ability to evaluate our own ideas and actions, then this capacity is similar to moral agency. However, simpler forms of rational thought can be advanced. Recall from Chapter 2 that Korsgaard (1996) claims that rational beings are merely those beings who can value ends in life, aside from instinct. The ends valued may be simple ones such as going out for walk in the garden for pleasure. This capability to value one’s own ends requires self-consciousness but does not necessarily imply a large amount of reflection by the rational being.

Parfit (1984) argues that having an adequate amount of **psychological continuity and connectedness** is an also an essential element of what matters to us. If there are fewer strong psychological connections between the current and past psychological life of the associated body (and the psychological view of personhood is accepted) then the level of connectedness may be too low for personhood in any meaningful sense to remain intact.

Arguably, a view that combines continuing psychological existence with the ability to value that existence is a promising approach to grounding personhood. Along these lines, Harris (1985: 14) proposes that a person is a ‘...being capable of valuing its own existence.’ This leads him to describe this rudimentary form of self-consciousness as the key property that defines the value of persons. In other words, if one is capable of valuing one’s own existence then others must too. Even if the person chooses not to value their existence, the fact they have the (self-conscious) psychological capability to do so means that others are compelled to see their value as persons.

### 3.4.2 Basing personhood on self-consciousness

Agreement on the centrality of self-consciousness can be found in Glover (1988: 61) who states:
‘I want to suggest that a prime feature of personhood is self-consciousness. A person is someone who can have thoughts, whose natural expression uses the word ‘I’

The suggestion can be made that this form of self-consciousness as valuing is possible for all except those with the severest dementia. Some support for this idea can be found by returning again to the work of Jaworska (1999). Jaworska claims that people with Alzheimer's disease have a basic capacity to value that is maintained longer than other capacities. It is worth recalling that Jaworska is primarily concerned about autonomy and goes on to state that this can only be achieved in a full sense if reflective capacities also remain.

Harris (1985) though, is setting a less robust standard for personhood as the level of cognition required here is only that which is necessary to value one's own existence. There is seemingly no requirement for the level of reflective thinking to be as high as for autonomous personhood, which involves the ability to scrutinise one's values in the context of being part of a community of other persons.

How might someone's personhood be respected if it is understood in terms of them merely having a continuing existence that they are aware of and are capable of valuing? It suggests a prohibition on killing. In the context of dementia care, this prohibition may be considered obvious; though, as will be discussed below it cannot be taken for granted.

What else might be suggested by respecting someone's personhood in this way? Glover (1988) states that self-consciousness produces an interest in past, present or future events that are going to affect me. Self-conscious beings make sense of themselves from information gained through perception of the world around them. Language is an important source of information (Harris 1985), which implies that respecting self-conscious beings means providing them with truthful information. So it is possible that truth-telling is not just necessary to respect autonomy in terms of facilitating decision-making, as discussed in Chapter 2, but also has a role to play in respecting someone's personhood more broadly understood.

To illustrate, let us reconsider the example raised in Chapter 1 from Schermer (2007). A woman with dementia, let's called her “Jane”, bangs on the door of a locked ward
begging to be let out to collect her long since grown-up children from school. It is found by people caring for Jane that telling her the truth makes her distress worse; whereas saying her children will not be out of school for an hour eases the distress. This example indicates that Jane is self-conscious in the sense that she can envisage an immediate future with her children. However, she is unable to accept truthful information that this future is not possible, perhaps due to an inaccurate belief about her age.

When considering a response, it appears that attempting to provide Jane with truthful information is the most respectful thing to do. Tuckett (2012) argues that truth-telling should be considered as the first option. Yet, in this case this seems like a futile and potentially harmful act. The best approach appears to be to respect the current self of which Jane is conscious, even though it is based on factual error and could therefore be considered a lie. Tuckett (2012: 17) agrees that a ‘therapeutic lie’ in such circumstances can be a compassionate response when other strategies, such as attempting to distract the individual, have failed. This also produces beneficent consequences, as it is stated that sharing her current version of reality allows Jane to talk about her children and this calms her distress.

For the purposes of this chapter, these consequentialist concerns, or a response based in compassion, should not be what determines the course of action; the aim here is to respect personhood. So, if Jane’s self-conscious personhood is to be respected then it must be done by acknowledging a broader sense of truth than is objectively understood. Personhood may be respected in such cases by validation of emotion and validation of Jane’s subjective reality. Arguably, though, doubt could still be cast on whether Jane is able to value her future in the meaningful way that the view of self-consciousness requires.

In order to try and get a definitive answer, the effect of dementia on self-consciousness has been investigated empirically. Psychological testing by Gil et al (2001) using a questionnaire method brought the following conclusion:

“AD [Alzheimer’s disease] clearly induces an alteration of self-consciousness, but not a total abolition, so that it cannot be said that patients are unaware of existing or more generally that reflexive consciousness no longer exists.”
Support for this is found in a systematic review of both qualitative and quantitative approaches for investigating self and identity in dementia more widely (Caddell & Clare 2010: 125), which concluded that “...the vast majority of evidence points to the persistence of self, at least to some degree, throughout the course of dementia”. In particular, a number of the studies reviewed found that people in the moderate to severe stages of the disease still commonly used both ‘I’ and other personal pronouns which indicates a level of self-awareness from self-consciousness.

This is supported by Eustache et al (2013) who found evidence that a sense of identity is maintained even when the disease is at its most severe. However, Eustache et al make a distinction between an awareness of sameness and selfhood. The former which is about preserving a basic sense of identity is preserved but the latter requiring the update one’s sense of self based on an assessment of the current situation is lost when dementia is severe.

Also, the findings from the studies reviewed by Caddell & Clare (2010) were equivocal. They state

“.....the majority of these studies focus only on people with dementia who have intact verbal abilities, which is likely to rule out many people in the severe stages of the illness and therefore again limits the generalizability of results. It is also worth noting that these studies tend to search for evidence which supports the persistence of self, rather than a deterioration in self, which could reflect pre-existing beliefs of the researchers regarding the effect of dementia on the self.” (Caddell & Clare 2010: 124)

This suggests some unreliability in findings, perhaps biased by people wishing to establish self-consciousness using such empirical measures. As such, it could be an overestimation of the level of self-consciousness is produced due to a wish to avoid the implications of loss of personhood for those with a psychological view.

Finally, there is some debate about the reality of a clear division between self-consciousness and simple consciousness. From a phenomenological point of view, self-consciousness, when understood as a non-reflective notion, is merely part of being conscious (Gallagher & Zahavi 2010). In other words, it is impossible to be conscious without having self-consciousness in this minimal form of being a conscious self-perceiving individual in the world (Kriegel 2004; Gennaro 1996).
3.4.3 IMPLICATIONS OF BASING PERSONHOOD ON MINIMAL PSYCHOLOGICAL CAPABILITIES

Efforts have been made here to understand self-consciousness as the notion of the individual being able to perceive themselves as a separate subject by using ‘I’ and being able to value that continuing existence. There is evidence that many people with dementia meet these criteria. This makes self-consciousness a more inclusive notion than autonomous personhood discussed in the previous chapter. The proposal that personhood is granted to those who are able to value their existence is reasonable in the sense that would provide basic protections and entitlements such as a right to life and not to be harmed. However, other aspects of personhood such as freedom of movement and the right to be told the truth might be harder to maintain as prima-facie duties.

Also, there are people who have a more severe form of dementia who may not be able to fulfil Harris’s criteria of being able to value their own existence. People in this situation will have sensory and perceptual awareness (Clare 2010) and may have a form of existential continuity as proposed by Dainton (2014: 77) which consists of ‘felt flow of experience from moment to moment’. However, it raises the question of whether it is plausible to extend the full range of protections and entitlements associated with personhood to human beings in this situation.

As Perring (1997) points out, in order to be consistent, such a commitment would mean personhood also being granted to other higher animals. This would mean that these animals could not be killed merely to feed human appetites nor harmed in order to promote human convenience or pleasure. It would be forbidden prima facie to use these beings merely as means to our own ends. This outcome would require a vegan diet but would also seriously restrict other human behaviours where animals could be harmed.

One possibility for making more plausible such a view of personhood based on sentient consciousness is to advance that it is only sufficient for personhood if the animal is both sentient and human. Although this may fit with common beliefs, it can be challenged as being prejudiced against other species (Singer 2011; 2009). The challenge is that appealing to the attribute of being a separate species is an arbitrary way to discriminate; in the same way that is considered arbitrary to discriminate based on skin colour or gender. Put simply: being human may not be enough. However, if compelling
reasons could be found why such biological differences are important, then these would nonetheless lie outside a purely psychological view.

Another strategy is to propose that the sort of consciousness non-human animals have is open to debate and therefore it may still be valid to discriminate based on the fact that non-human animal consciousness is somehow different to human animal consciousness (Harrison 1991; Nagel 1974). However, it is unclear how this might differ and the debate allows for either result, in the sense that non-human animals may or may not be persons.

So, although inclusive of people with severe dementia, there is seemingly a problem on the psychological view with including people with this level of psychological ability as persons in the psychological sense. It needs to be shown how minimal attributes are able to generate personhood. Also setting the threshold this low means including non-human animals or finding some valid distinctions in order to exclude non-human animals.

In summary, if personhood is viewed as all-or-nothing notion based on sufficient conditions then this creates the risk of unjust exclusion or inappropriate inclusion. There is also the difficulty that having an all-or-nothing version of personhood invokes a response that is not differentiated for different psychological abilities. Should the response to personhood generated merely by consciousness be the same as the response generated by full moral agency? It seems implausible that a being who is unable to reflect or communicate can have all the same protections, entitlements and responsibilities as someone will full moral agency. This implies the possibility of greater and lesser personhood. It is to this notion that the final section will turn.

3.4.4 PERSONHOOD AS A CLUSTER CONCEPT AND A MATTER OF DEGREE

Due to the unsatisfactory nature of determining a single threshold for personhood, a number of writers have proposed that personhood may be better understood as a matter of degree. Above, Glover (1988) stated that self-consciousness was the prime feature of personhood. He develops this view to argue for self-consciousness and personhood as being matters of degree. This account leaves open the possibility of degrees of self-consciousness, due to there being different kinds and degrees of I-thoughts with the result that being a person may sometimes be a matter of degree.
In a similar move Perring (1998: 193) argues:

‘Decisions based on degrees of personhood may be painful and even dangerous. However, there may be occasions where these judgments are justified.’

Others like Tooley (2012) also accept the possibility, while DeGrazia (2008) argues against dogmatic assertions, either that moral status admits to degrees or that it is all-or-nothing. Nonetheless, DeGrazia (2008: 193) does see personhood as a cluster concept serving as a ‘summary placeholder’ for ‘morally relevant properties’ such as autonomy and self-awareness, each of which he claims come in degrees.

In a sense the argument has come full circle. As pointed out by Perring (1997), the work of Parfit (1984), on which the contemporary psychological view strongly relies, suggests that persons are merely degrees of psychological connectedness. In this sense the more connected we are, the more we are persons and the more valuable it is for these psychological connections to survive.

For this investigation, the pertinent question is the implications of such a view for people with dementia. Glover (1988; 1977) hopes that moving to an understanding of personhood as being a matter of degree will reduce the arbitrariness of placing a sharp boundary between person and non-person. However, the remaining uncertainty relating to which properties count, and how much for, does not seem to resolve the issue of how to ground personhood (in a meaningful sense) for people with severe dementia.

A practical implication is that even if it is accepted that personhood has degrees, the resulting decisions may still be all-or-nothing. There are countless examples where a response, such as opening a locked door, getting someone out of bed, telling the truth, appears all or nothing. This suggests that even if a view of personhood is held that it can be in degrees, there may well be thresholds where certain entitlements (e.g. to be told the truth) take effect. In this view, personhood is understood as a matter of degree but it still invokes a range of prima facie duties. The nature of these obligations will vary depending on the degree of personhood present. On this view people with severe dementia may still be seen as persons, but they will be lesser persons.
There is a strong intuition that associates psychological connections with the moral status of personhood. On closer investigation it has been suggested that the most plausible psychological attribute sufficient for personhood is a simple form of self-consciousness where people are able to value their continued existence. This then creates prima facie duties on care providers towards the person with this attribute. In practical terms, a flexible approach may be required. For example, it may be that a prima facie duty to tell the truth yields to merely validating someone’s subjective conscious reality rather than truth as objectively understood.

However, the presence of self-consciousness is more doubtful for people with severe dementia, due to reduced psychological capacities and empirical uncertainty about what people in this state are actually able to think. If personhood is founded on simpler forms of consciousness then this approach produces a demanding moral vision. This is because, in order to be consistent with a purely psychological view, it must extend prima-facie protections and entitlements to non-human animals with similar psychological abilities.

A reasonable response is to suppose that personhood is a matter of degree. People (and other animals) with different levels of personhood will incur different prima facie duties from a care provider. If the duties incurred are all-or-nothing, this then results in each one having a separate threshold with a different degree of psychological ability needing to be met. This produces a worry about whether it is then possible to work out the placing of these thresholds. For example, how much of a person should someone be before they are entitled to be told the truth? This would result in a complex picture from which to produce an ethical model. However, things are potentially complicated further by the possibility that compromises are possible that reflect the degree of personhood present.

Ultimately, the psychological view of personhood is based on the premise that moral status is grounded on psychological capacities. As dementia involves a reduction or loss of these capacities, there is always going to be the risk of depersonalisation, although people may disagree whether this occurs or when it occurs.
Someone with a psychological view of personhood might regard this (coldly) as a matter of fact and therefore not a problem that can be addressed. However, Post (2013:154) describes such a view as having ‘[a] bias against the deeply forgetful’. Before going on to discuss the response to the psychological view, the effects of depersonalisation of people with dementia by society will be outlined.

3.5 DEPERSONALISATION BY SOCIETY

Nearly everyone who has dementia has lived a long adult life as a person. The psychological view has suggested that the progression of dementia can result in the individual no longer having an equivalent moral status, as their psychological capacities reduce. A plausible way of understanding this is that as dementia advances, the range of prima facie duties to people with dementia also reduces.

This leaves people with dementia in a much more vulnerable position than that of full persons. An extreme example of the implications of this is provided by Cooley (2007) who suggests, from his interpretation of Kant, that persons who are aware that they are going to develop dementia have a duty to commit suicide in order not to allow the body to live in a state devoid of moral agency. Clearly, Cooley believes that personhood is absent once the ability to exercise moral agency is lost, and this results in what he himself recognises could be thought of as a ‘too cold and uncaring’ position (Cooley 2007:43).

A number of scholars have criticised Cooley, both in terms of the cogency of the argument, its consequences and the quality of the Kantian scholarship on which it is based (Sharp 2012; Latham 2007; Perry 2007). Nonetheless, it demonstrates what might be considered the sharp end of the psychological view for people with dementia, and has relevance due to a recent rekindling of the debate regarding the permissiveness of non-voluntary euthanasia or so-called mercy-killings of people with dementia (Johnstone 2013; Sharp 2012).

As, Sabat (2006) points out, with the advance of dementia, people with the condition are increasingly unable to defend themselves against being negatively positioned in social situations. As a result, there is a tendency to interpret the behaviour of the person with dementia in increasingly ‘defective terms’ (Sabat 2006: 290). Sabat describes this as
malignant positioning which can develop into a *malignant social psychology*, as outlined by Kitwood (1997; 1990), against people with dementia.

It seems that people with dementia can be disenfranchised in a number of interrelated ways. If a psychological view of personhood is held then the number of prima facie rights is reduced. With fewer protections, people with dementia may also find themselves unable to resist the unwanted interventions that may result due to a reduced ability to communicate their wishes in these invalidating environments. Furthermore, it is argued by Kitwood (1997; 1990) that malignant social psychology actually causes further deterioration of the cognition of people with dementia. This then becomes self-reinforcing as the cognitive abilities of the individual with dementia are reduced by the environment leading to an increase malignancy in response to this further reduction in cognitive ability.

In concrete terms, Kitwood (1997: 46-7) highlights seventeen behaviours resulting from personhood being undermined by a malignant social psychology. Some examples are illustrated below and examined in terms of the discussion on psychological view of personhood above:

**Treachery**: Kitwood describes this as ‘using forms of deception in order to distract or manipulate a person, or force them into compliance’ (1997: 46). It is notable that Kitwood links deception and treachery. The example that Kitwood (1990) originally gives illustrates this link. It describes a woman with dementia being tricked to get into a car with a lie in order that she can be taken to the local psychiatric hospital.

In terms of the discussion thus far, Kitwood suggests here that the woman in this case has a right to be told the truth about the proposed destination and given a choice about whether she gets in the car or not. In everyday life, fully competent persons would expect this, otherwise such an action would be considered abduction. Yet, it still seems reasonable to suggest that in the event of the woman with dementia being at risk of serious harm (of which she cannot be made unaware) it is reasonable for her to be

2 A full list can be found in Appendix A
taken to a safe place. Nonetheless, it is arguable that this should be done without deception or treachery, if reasonably possible.

**Infantilisation:** Kitwood describes (1997; 1990) this as treating someone patronizingly as they would a very young child. The psychological view appears to be involved here as it is thought someone who is perceived to currently have a mental capacity similar to a child should therefore be treated like one. In real terms this treatment involves ignoring the adult person’s entitlement to respect in terms of polite language and recognition of their abilities, past and present. The use of dolls in therapy is one example where concerns about infantilisation have been raised (Mitchell & Templeton 2014; Andrew 2006). Themes here are also closely related to discussions on human dignity, and will be considered in more depth in the next chapter (4.6).

**Invalidation:** Kitwood (1997: 47) describes it as ‘failing to acknowledge the subjective reality of a person’s experience...’ As discussed above, personhood can be grounded in someone being conscious of their own subjective reality, even if it is not shared by others. Those that doubt the legitimacy of a subjective self-conscious reality may well be inclined to invalidation as Kitwood describes.

**Ignoring:** This is where people in close proximity to those with dementia behave as if they were not there. Perhaps this is because of a belief that the surrounding people with dementia cannot perceive or understand and so it is of no consequence. This exclusion implies a view that people with dementia are actually not present in a sense that requires a social response, except to service their bodies in an impersonal manner. This links to objectification, another element of malignant social psychology, where the individual is seen as a ‘...lump of dead matter: to be pushed, lifted, filled pumped or drained...’ Kitwood (1997: 47).

In a related move, it is suggested by Aquilina & Hughes (2006) that people with dementia can be treated by society as if they are already dead. This can be termed a ‘living death’ (Hill 2008) or a ‘death that leaves the body behind’ (George 2010: 586). Indeed, Davis (2004) talks about the benefits of relatives beginning a grieving process during the phase of cognitive decline. However, others argue that these expressions are now increasingly a thing of the past (Nuffield Council on Bioethics 2009a; Downs 2005). It is likely that describing the human being with dementia as dead is merely a
metaphorical way of saying that the remaining psychology no longer resembles the person once known. After all, people with dementia do not meet the criteria for death, which Belshaw (2009:16) defines as ‘... the irreversible breakdown of the organism as a whole.’

The meaning behind such expressions might also be linked to the notion of the social death that the person undergoes before biological death (Sweeting & Gilhooly 1997). In this sense, the individual is considered not to be alive in any meaningful sense by those around them. The perceived loss of personhood results in a social death which removes the protections and entitlements that are expected as an equal citizen (Brannelly 2011).

Underlying much of the above, is the philosophical view of social constructivism that sees the human self and its personhood as being constructed by society rather than solely existing due to the individual’s mental processes (Hughes 2011a). This offers a way out by offering a different way for society to understand and interact with those who have dementia, in order to remove the social malignancy and thus to a reconstruction their personhood.

3.6 RESPONSES TO DEPERSONALISATION

3.6.1 PERSON-CENTRED CARE

In his landmark book Dementia Reconsidered Kitwood (1997) states how he was motivated to a response after observing the phenomenon of malignant social psychology. Along with a colleague, Kathleen Bredin, they decided that a new culture in dementia care was needed which would focus on maintenance and enhancement of personhood rather than pathologizing people based on cognitive impairment (Kitwood 1997:136; Kitwood and Bredin 1992).

This new approach was entitled person-centred care, based on the original Rogerian psychotherapeutic term. Though, philosophically, it also draws heavily from the work of Martin Buber who saw personhood as being founded in the response to our spontaneous relationships to other human beings (Baldwin 2008; Kitwood 1997).

Person centred care, has since been advocated widely as a model of dementia care both in the UK and abroad (Edvardsson et al 2008; Brooker 2007). However, it is arguable that a situation has developed where person-centredness has merely become an
exercise in political correctness rather than having substance for many that use the term in practice (Brooker 2004).

Kitwood was aware of the need to counter philosophical views that emphasise individuals’ psychological capabilities. Drawing on the work of Post (1995), Kitwood proposes that the answer must be inclusive of everyone with dementia. As Kitwood (1997: 10) emotively puts it:

‘[Despite differences in mental capabilities] we are all, so to speak, in the same boat; and there can be no empirically determined point at which it is justifiable to throw some people into the sea’.

Rather than psychological capacity, Kitwood suggests that personhood is based on three elements: uniqueness of persons, embodiment and relationships with others. This can be observed in his oft-quoted definition of personhood:

‘It is a standing or status that is bestowed upon one human being, by others, in the context of relationship and social being. It implies recognition, respect and trust.’ (Kitwood 1997: 8)

It is argued by Brooker (2007) that Kitwood’s original vision has been obscured by government policy in the National Service Framework (Department of Health 2001) that interprets person-centred care merely as individualised care rather than focusing on communication, relationships and the culture of care as Kitwood originally intended. This had led some to call for relationship-centred care as a development from person-centred care (Nolan et al 2004; Nolan et al 2001), seemingly overlooking the central position held by relationships in Kitwood’s original psychotherapeutic vision.

Nonetheless, this original vision of Kitwood is open to criticism. Firstly, there is the worry of whether it is consistent to hold the view that personhood can reflect uniqueness without also being individualistic. If the individual is the focus, then it seems that this undermines the relational nature of Kitwood’s proposal. Yet, Kitwood can be defended here as it seems reasonable to posit that individuals can be unique and interdependent. In other words, there is a distinction between independence and individuality; people can be unique individuals but still depend on their relationships with others.
Secondly, there has been criticism of the rigour in Kitwood’s methodological approach (Dewing 2008). Also, due to his untimely death, Kitwood was unable to fully clarify his philosophical position. Nonetheless, its enduring influence in the field of dementia care suggests that people have found Kitwood’s analysis persuasive nonetheless, and Dewing (2008) adds that a broader reading of his work reveals a cogent approach.

A final and more serious problem relates to Kitwood’s definition of personhood. This is of central interest here. Recall, that his definition states that personhood is bestowed upon a human being by others. It is notable that in his seminal work Kitwood (1997) does not return to bestowing, and instead focuses on maintaining personhood, which contains the tacit assumption it is there.

Nonetheless whether the focus is on bestowing or maintaining personhood, the end result is the same. The key thing is that people with dementia are being somehow provided with this status by others. Yet, in order to be inclusive, the question is raised what it is that will ensure that care providers bestow or maintain personhood for everyone with dementia.

In order to explain why, Kitwood (1997:61-4) makes the empirical claim that carrying out person-centred care (or positive person work) slows cognitive deterioration and improves well-being. These positive outcomes provide a reason to bestow or maintain personhood but there is no argument here that obligates people to do so. There could be one or a number of people who decide, for other reasons, not to bestow or maintain personhood for certain individuals with dementia. For example, they may believe that the well-being gained by bestowing such a moral status is not as great as the burden of the extra work needed to respect this status and therefore they choose not to bestow personhood or provide the associated care.

Kitwood’s work can be aligned with social constructivism. This commonly understands personhood as something constructed by others through social interaction (Hughes 2011a). Yet, the notion of malignant social psychology illustrates how such forces can also depersonalise people with dementia (Aquilinia and Hughes 2006). Furthermore, the thesis of social constructivism that all psychological phenomena are merely social constructs is debatable (Hughes 2011a; 2001a). It appears that leaving it up to others to bestow personhood makes it a potentially exclusive notion after all (Dewing 2008). To
rephrase Kitwood's words above: if left up to the crowd they could after all decide to throw someone out of the boat.

Kitwood's view is undoubtedly an influential force in dementia care. It promotes a positive attitude but its grounding for personhood is open to challenge leaving the position vulnerable to being eroded by those who believe that some people with dementia are not persons.

Despite this, it is important to stress that Kitwood’s work is not being dismissed. As described above, his writing also suggests personhood is maintained through the process of forming relationships with people with dementia and recognising their uniqueness as human beings. This suggests a more existential argument which begs further investigation. Kitwood's work also contains some important insights into how interacting on an emotional level with people with dementia can develop certain qualities or virtues in the care provider. It is possible that development of the care provider’s character and empathic receptivity is the key factor.

Finally, it is possible that there is actually consequentialist ethics smuggled in by the claim that bestowing personhood improves wellbeing and possibly also delays the progression of the disease. A role for consequentialist ethics will be returned to in Chapter 8.

3.6.2 SITUATED EMBODIED AGENT VIEW AND ‘BODILY AUTONOMY’

Hughes responds to the psychological view of Locke and Parfit with the situated embodied agent (SEA) view of the person. In doing so, he draws on the work of existential phenomenologists Heidegger and Merleau-Ponty, along with the work of Wittgenstein (Hughes 2013; 2011a; 2001a). Similarities can be seen with the approach of Kitwood (1997) in the acknowledgment of a social context, but Hughes distances himself from the full-blown social constructivism implied by Kitwood (Hughes 2011a; 2001a). As the name suggests, Hughes’ view has three components: situated context, embodiment and agency.

In describing his view Hughes (2011a: 42) states
‘In its most general form, the SEA view suggests that psychological phenomena are properly understood only in a contextually embedded manner: they cannot be characterized independently of the situated context.’

By this Hughes means that the context in which we live, such as family and culture is an essential part of understanding the person and the meaning behind the person’s communication. Due to this situatedness, persons cannot be understood merely as a series of psychological connections but are also embedded in a broader unified narrative (Hughes 2011a; 2001a). Hughes also writes also about the role of spirituality in the SEA view. Drawing on Heideggerian terminology, he states that seeing human beings situated in a spiritual domain ‘...is a non-negotiable aspect of our being-in-the-world’ (Hughes 2011b: 204). However, the emphasis in Hughes’ philosophical work is on the secular notion of being embedded in social terms (Hughes 2011a; 2001a).

The SEA view suggests a social narrative view of the personal identity, such as was discussed in Chapter 2 in the context of autonomous personhood. Recall in that context, the worry was that a social view would subsume the individual’s wishes. Without the need for autonomy, there is arguably less of a problem with someone’s narrative identity being a more social notion. However, as Hughes recognises, for the narrative view of personal identity to work it is necessary to identify with a continuing human body. Putting this in the context of advance directives, Hughes (2001a: 89) states

‘For the reality at the bedside suggests, in keeping with the SEA view, that this person today is continuous with and connected to the person who signed the directive, by embodiment and by the situatedness that embodiment entails.’

To support the centrality of embodiment, Hughes (2013; 2011a) draws on the existential phenomenology of Merleau-Ponty (2012/1945), which proposes that our understanding of the world is essentially that of an embodied being, and that we can only act in terms of this embodiment. This acts as a rebuttal to the Locke/Parfit view of personal identity by instead understanding identity as arising from a situated embodied context rather than individual’s psychological states (Hughes 2011a).

This emphasis on being human rather than the psychological life as the main source of personhood finds support in the work of Buber, a Jewish theologian, which also influenced Kitwood’s philosophy. It is also a common line of argument in Christian bioethics to rely on the notion of being human as the key source of moral status,
regardless of a particular individual's faculties (Sutton 2007). Hughes (2008: 129) appears to be suggesting something close to this position when he states that

‘The arguments here suggest that people with dementia, because we all occupy the same human worldly groove, remain persons even in the severer stages of their disease. The requirement that we should be person-centred, therefore, stems from our being human.’

As it stands, a tendency to focus on embodiment leaves the position vulnerable to accusations of speciesism (Singer 2009) as it is unclear what is about being biologically human that grants moral status. However, it is clear that tapping into our shared human experience means we have a chance of better understanding those of us who have dementia by ‘a potential to feel their meaning’ when language fails (Hughes 2013: 356).

Nonetheless, despite a providing an eloquent phenomenological description of what it is to be human, it remains unclear how sharing the experience and language of being human generates a moral status for persons. Recall, that a similar criticism was used in the previous chapter against Agich’s (2003) view of actual autonomy that also drew heavily on a phenomenological view. However, the importance of feeling in dementia will be returned to later when the discussion moves away from the focus on moral status.

A number of possible avenues are open at this point. Discussions on human dignity as, the name suggests, focus more on humanness than personhood. There is also recourse to arguments drawing on a spiritual or an existential view of human existence. Although there are clearly links between these arguments and a discussion of personhood, they will be given a full treatment in the next chapter.

Leaving these elements to one side, it is possible that the answer may be found in agency, the final aspect of Hughes’ framework. As recognized by Hughes (2011a), agency is primarily associated with autonomy; yet, this immediately creates a problem as this is not an ability that is shown by everyone with dementia. In a similar move to the Nuffield Council on Bioethics (2009), Hughes (2011a) goes on to suggest that autonomy should be seen as relational and interdependent. However, in Chapter 2 it was argued that this does not solve the problem as its reliance on a social view proved unreliable, risking equivocal results.
So some further thinking is required on how agency fits into the picture of grounding personhood for people with severe dementia. Hughes (2011a; 2001a) stresses that people with dementia, along with the rest of us, are not just agents but situated embodied agents. This means that certain gestures, even in severe dementia, can be understood as agentive with the aid of having this shared embedded context (or human worldly groove). Hughes (2013; 2011a) also draws on Wittgenstein’s notion of an agreed form of life to make the point that understanding is more than just a cognitive act by drawing on our whole experience of being human.

To help illustrate the point, both Hughes (2013; 2011a) and Dekkers (2004) use the example of someone with severe dementia seemingly rejecting the intervention of artificial feeding. The thought is that the physical resisting of these interventions is significant, rather than merely a reflex against such an intrusion. In this context, Dekkers (2010; 2004) argues for the notion of bodily autonomy. Dekkers (2010: 257) uses the term autonomy in a particular way to suggest that ‘the human body lives its own life’. Along with Hughes, Dekkers (2010; 2004) aligns his work with the philosophical heritage of Merleau-Ponty (2012/1945). Dekkers (2010: 258) argues that even in severe dementia there is the preservation of

‘[t]acit bodily knowledge.... based on the sedimentation of life narratives...' finding their expression in behavioural patterns which ‘....may be interpreted as a remainder of what once has been ‘real’, that is rational autonomy.’

Yet this distinction between rational autonomy and bodily autonomy suggests a two tier approach to autonomy that is ultimately unhelpful for grounding personhood for people with severe dementia. Indeed, Dekkers (2010: 254) makes it clear that his ambitions are limited when he states.

‘My position is that people with severe dementia cannot be entirely denied a (rudimentary) form of selfhood or personhood. They definitely are not persons in the strict sense of moral agents who are self-conscious and rational and demonstrate a minimal moral sense, but at least they can be called persons in a weaker sense.’ [my emphasis]

So although people with severe dementia may be called persons, arguably, they should be denied anything more than a rudimentary form of personhood in a moral sense.
Earlier in the same chapter Dekkers also states ‘...my own premise is that ‘person’ is equivalent to ‘human being”. (Dekkers 2010: 253) It is hard to deny that people with severe dementia are human beings. So to reconcile this, it would appear that Dekkers is taking the position that all human beings are persons in a descriptive sense but, in terms of their moral status, people with severe dementia are (at best) lesser persons than the rest of us. As a result, Dekkers’ work appears to bring us no further forward than the psychological view described above for grounding personhood for people with severe dementia.

So where does this leave the SEA view? It was hoped that agency might be able to form a more solid grounding than merely relying on situated embodiment human life. However, it appears that agency is not something that can ground personhood for people with severe dementia. Advance directives can be used, but these are vulnerable to previously elaborated criticisms on how narrative identity can survive. At this point, it appears that the agency component is unable to secure the triad as a whole.

In summary, the SEA view enhances the phenomenological understanding of the person with severe dementia. As a result, the insights drawn on are useful for improving care. However, it does not seem meet the aim here of grounding personhood as a moral status. Nonetheless, shared human experience and dignity may well form a suitable basis for an ethical model.

3.7 EVALUATING THE ROLE OF PERSONHOOD IN AN ETHICAL MODEL FOR DEMENTIA CARE

In the previous chapter it was argued that psychological views of autonomy are unable to ground autonomous personhood if mental capacity is not sufficient for reflective thinking. Attempts to solve this problem from non-standard views of autonomy, precedent, relational and phenomenological, ultimately proved unconvincing. Although there may still be a role for autonomy and autonomous personhood in a broader ethical model, autonomous personhood has not been able to ground solely a model for dementia care in a fully inclusive way.

It was hoped that unbuckling the requirement of autonomy from personhood might broaden its inclusiveness sufficiently to include most, if not all, people with dementia.
On this broader psychological view, it was suggested that the most plausible attribute sufficient for personhood was self-consciousness. This appeared a promising move as both philosophical and empirical work suggested that most people with dementia are self-consciousness in the sense of being able to value their continued existence.

It has been shown that having self-consciousness as the necessary and sufficient criterion of personhood provides the status to more people than autonomous personhood. This creates prima-facie duties on care providers towards the person with dementia. It also allows the valuing of the simplest of ends to be respected even though autonomous decisions that require reflective thinking based on an awareness of broader factors in one’s life may remain out of reach.

However, the presence of self-consciousness is more doubtful for people with severe dementia, due to a further reduction in psychological capacities. There is some evidence that a basic sense of identity based on simpler form of consciousness continues into severe dementia (Eustache et al 2013). Yet, if personhood is founded on simpler forms of consciousness then in order to be consistent with a psychological view, it must extend prima-facie protections and entitlements also to non-human animals with similar psychological abilities. It was argued that this creates an overly demanding moral vision beyond that which can be expected by such attributes.

As a result, rather than understanding personhood as an all-or-nothing notion based on sufficient conditions, it was suggested that it might be better understood as being a matter of degree. Linking this to the notion of prima facie duties, it can then be proposed that people with different levels of personhood will incur different prima facie duties from a care provider. It is possible that different levels of personhood will allow for certain compromises to be allowable that otherwise would not be if a greater level of personhood was present.

However, this approach produces a rather complex configuration with each duty effectively having a different threshold of psychological ability that must be reached in order for it to be engaged. This did not meet the overarching aim here to produce an ethical model that is both practically useful as well as being philosophically rigorous.

So it was concluded that despite moving away from the need for autonomous personhood, the psychological view is not the best way to ground an ethical model for
people with dementia. In fact, it was advanced that focusing on psychological properties might be harmful, leading to depersonalisation and a malignant social psychology.

This led the discussion onto two prominent responses to the purely psychological view: person-centred care from Kitwood (1997) and the SEA view of Hughes (2011a; 2001a). There is much to recommend both of these views; in fact, it is fair to say, that following either approach could enrich the provision of dementia care. However, in terms of the work needed here to establishing personhood as a moral status, it is argued that both views leave too much uncertainty to generate an ethical model.

Kitwood's view relies on people recognising the uniqueness of each human being through relationship and suggests that this can slow the progression of dementia. Yet, Kitwood is open to challenge due to apparently unreliable nature of bestowing a moral status in this way. If those caring for people with dementia do not wish to bestow personhood on them, there is no argument in Kitwood that obligates them to do so in terms of moral status, though it does suggest some other existential and consequentialist reasons to do so.

Hughes' view hopes to overcome the flaws in this and other social constructivist positions of personhood. However, although this generates a persuasive phenomenological position on what it is to be human (with or without dementia), it remains unclear at this stage how sharing the experience and language of being human generates a moral status on which an ethical model can be built. In order to so this the central notion of humanness needs to be evaluated.
4 DIGNITY AND AN EXISTENTIAL UNDERSTANDING OF HUMANNESS

4.1 INTRODUCTION

Chapter 3 examined whether the criterion of self-consciousness might be sufficient to support a psychological view of personhood for people with dementia. Though this is more inclusive than autonomous personhood, it was argued that extending personhood to people with the severest dementia produces an overly demanding moral vision. This is due to the need to extend prima-facie protections and entitlements to non-human animals with similar psychological abilities in order to remain consistent with the psychological view. The alternative of imagining personhood as being a matter of degree was demanding in the sense that there are practical difficulties with trying to assign the appropriate levels of entitlements and protections to those with ‘lesser’ forms of personhood. So even if such a system of more-or-less personhood is possible, it did not meet the aim here of producing an ethical model that is practically useful.

In response, alternative views of personhood that seek to be fully inclusive of people with dementia were also investigated. A number of these views, such as Kitwood (1997) and Hughes (2011a) are prominent in the field and add a great deal to improve the care provided for people with dementia. Yet, these approaches were shown to be vulnerable to philosophical challenge. Kitwood’s view of personhood relies on others bestowing the status on the individual with dementia. This may be plausible within the context of a positive environment where people are willing to bestow personhood in this way. However, this may not be case in all situations. If those caring for people with dementia do not wish to bestow personhood on them, there is no argument in Kitwood that obligates them to do so in terms of moral status. Hughes’ view aims to overcome the flaws in this and other social constructivist positions of personhood. However, the position generated is not an argument for moral status per se. It is, instead, a phenomenological position.

4.1.1 BROADENING THE USE OF THE TERM ‘PERSON’

Despite these results, it seems fair to suggest that few people outside of philosophical circles would defend the notion that a living human being is a nonperson. Though, it is
possible to be caring towards nonpersons, to describe them as such implies a disrespectful and callous attitude to the human being concerned that would be particularly unacceptable in a caring context.

Perhaps for this reason, people with dementia in everyday care situations continue to be described as ‘persons’, without necessarily inferring they have the exalted moral status that comes with philosophical definition of that term (Sapontzis 1981). So, people with dementia, though called persons, may not have the same levels of protection, entitlements or responsibilities that come with having full moral status. For example, it may be considered acceptable to carry out certain necessary care tasks (such as washing), despite the person with dementia objecting. These interventions may still be carried out in a sensitive and caring manner, perhaps using coaxing rather than coercion. Nonetheless, a person with full mental capacity would have the right to refuse such an intervention as well as having the responsibility to accept the consequences of such a decision.

So this leads to question what do people mean when they say that an individual is a person? It is suggested here that they may be getting at something else, the notion of humanness or shared humanity. From this broad notion, the more specific notions of dignity and a variety of existentialist and more spiritual views can be drawn. There is no doubt that people with dementia are still human, even in the severest stages of the disease. The aim of this chapter is to assess what it is that people understand by the experience of caring for another human being and how this might ground an ethical model for dementia care.

The first section will explore how humanness, as ground for an ethical model, may be found in dignity. The multifarious concept of dignity will be thoroughly examined along with its relationship to autonomy. The second section will then pick up on themes raised in Chapter 3 on spirituality and existentialism and evaluate whether these concepts can be understood in a way that can ground an ethical model in dementia care.
4.2 DIGNITY AS A CONCEPT IN CARING

Dignity is a notion which is familiar in experience yet contested in definition. It is fair to say that most people are able to get a sense of the difference between a dignifying and undignifying situation for a human being. Shotton and Seedhouse (1998: 246) suggest that anyone who has found themselves in a ‘degrading situation’ knows what dignity is. In everyday life, we make efforts to do things such as protect the privacy of our bodies, present ourselves in an acceptable way, attempt to appear erudite in company or calm under pressure. There is a sense that we already know what dignity is for ourselves and this can be generalised to help honour it for others. In this vein, Seedhouse and Gallagher (2002: 369) describe an ‘intuitive understanding of dignity’ amongst care providers, patients and their relatives.

The way that people have expressed their understanding of dignity can be found in empirical studies, both from health professions and the wider community (Royal College of Nursing 2008; Stratton and Tadd 2005; Tranvåg et al 2013). Yet, Shotton and Seedhouse (1998) also suggest that without an adequate definition of the concept, there is a chance that dignity will not be given the protection it deserves in health care practice. This view underlies the overarching aim of this thesis which is to establish a philosophical grounding that best meets the challenges of providing an ethical model for dementia care.

The academic literature can be broadly divided into work that attempts to clarify the theory behind the concept and those studies that aim to deduce its meaning by investigating how people understand the term in practice. Gallagher et al (2008) argue that there can be a ‘dialectical relationship’ between theoretical work on the conceptual and empirical work, which suggests that the tension that can be found between dignity theory and how people experience the concept in everyday life can ultimately be productive. This dialectical view is accepted here as a sound strategy for developing an understanding of dignity. As a result, both empirical and philosophical literature will be considered in an attempt to find a conception of dignity that is conceptually rigorous while also matching people’s experience of being a dignified human being.

Dignity as a philosophical concept has strong historical roots. It was described by Aristotle as a virtue of character. Aristotle believed it could be cultivated by pursuing a
middle path that avoids excesses of deference to others and arrogance in ourselves, while also being neither subservient nor disrespectful to others (Gallagher 2004).

Dignity is also important in the ethical writings of Kant and plays a prominent role in human rights discourse (Gallagher et al. 2008).

Yet, in contemporary times, it has been subjected to criticism. Pinker (2008) states that the concept is not adequately defined, describing it as a ‘squishy’ and ‘subjective’ notion. He goes on to argue that it is not able to do the work required of it, particularly when it is being employed by conservative bioethicists. If Pinker is right, then this lack of theoretical grounding is a concern worth addressing.

The use of the term dignity also invites criticism when applied in a more liberal sense of protecting people from unwanted interventions of others. Macklin (2003) argues that despite its prominence in such bioethical discussion, it actually means no more than respect for persons or their autonomy and is therefore a redundant term. If Macklin is right, then dignity will not be able to provide any alternative to the problems of establishing autonomy and personhood for people with dementia, which have been described in the previous two chapters.

Responding to such concerns, the conservative commentator Leon Kass (2008: 300) is clear to point out that respect for human dignity...

‘...lies not in the patient’s autonomy or any other of his personal qualities or excellences but rather in the patient’s very being and vitality.’

However, in the same article, Kass appears to endorse the very difficulties he is trying to avoid:

‘In sum, the human being has special dignity because he shares in the godlike powers of reason, freedom, judgment, and moral concern, and, as a result, lives a life freighted with moral self-consciousness—a life above and beyond what other animals are capable of.’ (Kass 2008: 325)

This definition of a ‘special dignity’ suggests a Kantian view of dignity, where being a human person means possessing a special kind of absolute worth that cannot be exchanged or balanced with anything else. Yet, problematically the source of this worth and its resultant moral status is for Kant (no more and no less) the ability to choose with autonomy. For Kant, autonomy means having a rational will that is free and
therefore able to choose morally by deducing reasoned laws or principles that could be accepted by all (Johnson 2008; O’Neill 2002a; Kant 1996a/1785). Yet, this appears equivalent to the properties that Kass outlines for *dignity* above. So despite Kass’s attempts to avoid autonomy, his description of human dignity appears to be describing Kantian moral autonomy in all but name.

As Chapter 2 has found autonomy to be lacking in a meaningful sense for people with advanced dementia, following such an argument would suggest these individuals not only lack personhood but dignity too. Aligning dignity *absolutely* with autonomy brings the discussion no further forward. However, it may be that autonomy can play a role in understanding dignity without dominating the concept.

4.3 THE RELATIONSHIP BETWEEN DIGNITY AND AUTONOMY

The first aim is therefore to clarify the relationship (if any) between dignity and autonomy. Kant’s claim that autonomy is the sole source of dignity is contested. Pullman (1999) hopes to redefine ethics in long term care with dignity rather than autonomy as the primary idea. Yet autonomy still retains a central role:

‘Autonomy remains a central notion within an ethic of dignity, albeit as a value circumscribed by that broader notion.’ (Pullman 1999: 44)

Though, Pullman adds that the role that autonomy plays in some people’s personal dignity is due to the prevailing social climate rather than being an essential part of the concept:

‘Inasmuch as personal dignity is a socially constructed notion, the relative importance of individual autonomy to each person’s sense of personal dignity can never be taken for granted.’ (Pullman 1999: 35)

So, autonomy is not determining dignity absolutely as with Kant’s view but it remains an important part of dignity, at least in societies that value autonomy. There is some support in the empirical literature for this view that autonomy forms part of what it is to have dignity.

Tranvåg *et al* (2013) carried out a meta-ethnography of healthcare professionals’ perceptions of dignity and the practice of dignity-preserving dementia care. The results suggest that respect for autonomy does indeed play a role. For Tranvåg *et al*, the other
important factor was the notion of individual integrity. This is understood to mean the protection of one's personal sphere both physically and psychologically; maintaining the privacy of one's body and surroundings as well as being able to hold certain values (Randers & Mattiasson 2004).

Tranvåg et al (2013: 869) found that in the majority of the studies, professionals saw ‘...advocating individual autonomy and integrity as a primary foundation for dignity-preserving dementia care...’ An important part of this is care providers helping the person to maintain a ‘...sense of status in her or his own eyes...’ (Tranvåg et al 2013: 870). On the other hand, some studies formed the view that advocating autonomy could erode integrity in a way that is unacceptable for dignifying care, indicating a departure from the notion that autonomy is a source of dignity. In these situations, integrity takes precedence leading to ‘persuasion and/or mild restraint’ as a way of preserving dignity (Tranvåg et al 2013: 872). As the study from Randers and Mattiasson (2004: 70) puts it

‘Understanding the complexity of the concepts of autonomy and integrity in the care of older people may lead to the supporting or substituting of patients’ autonomy, in ways that protect their integrity and, consequently, uphold their dignity.’

A similar theme is found in (Jakobsen and Sørlie 2010: 296) who interviewed nursing home care providers.

‘Intervening against a patient’s will was for these informants motivated by the wish to promote dignity.’

However, it is important to recall from the arguments in Chapter 2 that autonomy is variously understood. The autonomy being ‘substituted’ here may not refer to autonomy in the deeper sense of being able to make a reflective choice. It may well refer to autonomy understood merely as freedom to choose. This sort of autonomy would not necessarily be seen as dignifying in the same way as pursuing autonomy in the deeper reflective sense.

A concrete example of this is using physical force in order to wash someone who is refusing to do so (Jakobsen & Sørlie 2010). In such situations, the individual has made a decision not to be washed. However, this may not be an autonomous decision in the deeper sense. After all, if this was actually an autonomous decision then such an
intervention carried out on an adult would be considered assault unless there was an appropriate legal authority in place. The alternative is that the refusal is not considered autonomous and therefore the care providers feel obliged to override it.

If it is believed that an autonomous decision is not possible then care providers may well look to the perseveration of dignity as an ethical justification for intervening in situations such as someone being washed. In their research, Örulv & Nikku (2007) found that the key decision for staff in care homes when encountering a dignity-threatening situation is whether they were justified to ‘interfere’ or not in order to preserve dignity.

Yet, this still begs the question of what the dignity is that is being honoured by such interventions. Discussing this and other similar examples, Tranvåg et al (2013) state that meeting patient’s personal hygiene needs is part of protecting the physical element of personal integrity. However, this seems somewhat at odds with the notion that integrity is about privacy and protection of personal space. Could it not be that someone’s dignity is violated more by being washed forcibly than by being allowed to stay unclean?

The concern here may relate to the very notion of allowing a human being to remain soiled. This suggests a more conservative notion of dignity, where the human body must be maintained and seen in a certain way. This possibility will be returned to later on.

There are other reasons for intervention, which may also be compelling, such as the overall well-being of the individual or those around them. However, this would not be responding to dignity as such but rather to consequentialist concerns such as promoting comfort for the greatest number.

This section has shown that the strength of the relationship between autonomy and dignity depends on how each of the terms is understood. The following sections will evaluate the difference between subjective and objective views of dignity as a way of differentiating the concept from autonomy.
4.4 DIGNITY AS A SUBJECTIVE NOTION

Following a comprehensive review of the literature Matiti and Baillie (2011) found that dignity is a multifarious concept. Furthermore, they suggest that everyone has a ‘unique and dynamic’ (2011: 21) understanding, inferring that not only does each individual’s definition of dignity vary but also it is in a state of flux. This is reflected in the definition of patient dignity from Matiti’s PhD thesis that states:

‘Patient dignity is the fulfilment of patients’ expectations in terms of values within each patient’s perceptual adjustment level, taking into account the hospital environment.’ (Matiti 2002, cited in Matiti and Baillie 2011: 14)

This definition appears to be based on a view that each person’s dignity has to be discovered before it can be responded to. This suggests a subjective view of dignity. The difference between this and objective views is an important distinction in discussions on dignity as objective views see dignity as something that exists independently of people’s subjective experience of the term (Gallagher 2004).

Yet, there is the possibility that following a subjective path brings the concept back again to autonomy. People make autonomous choices and these ought to be respected. However, if someone starts to lose the ability to form autonomous choices, it seems to follow that they are losing the ability to form their subjective dignity expectations too. This is because it appears incoherent to separate the forming of a dignity expectation from the forming of an autonomous choice.

In order to differentiate these, it would have to be possible to have a dignity expectation that is not an autonomous choice. However, it seems reasonable to propose that someone cannot expect a certain outcome based on their own understanding of dignity without this also being part of a reflection on how this fits an autonomous decision to live life in a certain way. Conversely, if someone believed that a course of action was subjectively undignifying it is unlikely that this course of action could then be chosen with autonomy.

One view of dignity that is relevant here is the dignity of identity proposed by Nordenfelt (2004). Though, rather than attempting to differentiate this from autonomy, Nordenfelt (2004: 75) outlines autonomy as one of its central components.
'It is the dignity that we attach to ourselves as integrated and autonomous persons, persons with a history and persons with a future with all our relationships to other human beings.'

As with a number of studies discussed in Tranvåg et al (2013) above, Nordenfelt states that the dignity of identity is grounded by both autonomy and integrity. This definition suggests a subjective view of dignity, linked (at least partly) to respecting autonomous personhood. To illustrate, Wainwright and Gallagher (2008) refer to Gallagher's (2004: 595) example of a woman who said that ‘...dignity to her meant having a saucer with her cup’. Such dignity expectations are described in subjective terms by Wainwright and Gallagher (2008: 52):

'The point is not whether saucers are of objective importance, or whether the woman is right to expect a saucer. It is that the woman’s preference, for reasons that have to do with her age, social class, her deeply held values and in short her identity, is to use a cup and saucer and her preference should, if possible, be respected.'

If we accept that saucers are not of objective importance, then it seems reasonable to infer that notions such as the woman’s preference, her values and identity are linked to her individual autonomy. So, this form of dignity is at risk once the ability to exercise autonomy in thinking and action declines. Furthermore, it has been argued in Chapter 2 that precedent autonomy on which advance directives rely is problematic; so following past preferences may not respect autonomy and therefore not this form of dignity either.

Wainwright and Gallagher (2008) agree that this apparent dependence on autonomy of the dignity of identity undermines the inclusiveness of this particular conception of dignity. Nordenfelt (2009) has responded in later work by stating that although this conception of the dignity is based on the subject’s integrity and autonomy, it is not solely reliant on their self-image. Nordenfelt states someone’s integrity can be perceived to have been undermined by society without the person being aware and this can bring about a reduction of the dignity of identity. This suggests that people have a dignity based in a social identity as well as a personal one. Though, this avoids the problem of tying dignity with autonomy, it generates new problems by dignity being socially relative. This will be assessed in the next section.
A further practical example of the relationship between dignity and autonomy can be found in Tadd et al (2011). They describe a situation where a patient on a ward asks to go to the lavatory but is told by the nurse to use an incontinence pad as it is unsafe for the woman to be assisted to walk there. This is highlighted as an ‘indignity’. However, when analysed more closely the example seems to turn more on a discussion of autonomy than dignity. The situation is one where an autonomous preference to go to the lavatory is deliberately thwarted by the nurse refusing to assist the woman concerned.

An alternative scenario can be proposed. Here the woman may autonomously choose to use a pad, accepting that this is the safer option. It seems more open to debate whether this would still be considered an indignity. To consider it so would rely on an objective notion of dignity linked to how humans ought to behave (in general). This could also apply to the saucer example above, if it can be shown that having a saucer with the cup represents something of objective importance for people from a particular culture.

A further possibility is that the woman in Tadd et al’s (2011) example may have dementia and be unable to express a preference one way or the other. If it is genuinely unsafe for the woman to be assisted to walk to the lavatory and also that some discomfort would be felt by using a pad, then a dilemma is created. It may well be impossible to know the woman’s autonomous preference in this situation and (as argued above) it is not possible to know her subjective dignity expectations either. It is therefore necessary to consider objective dignity concerns in investigating whether it is more of an indignity to be assisted to go to the lavatory or use a pad.

Thus far, it appears that autonomy has a strong influence on dignity, particularly when it is understood as a subjective notion. If autonomy is not possible, then this puts these subjective forms of dignity at risk of diminishing too. For people with dementia, exploring dignity as an objective notion appears a more promising avenue.

4.5 DIGNITY AS AN OBJECTIVE NOTION

4.5.1 ‘BASIC’ HUMAN DIGNITY

Objective forms of dignity propose that dignity is something that exists independently of people’s subjective experience of the term. The most obvious candidate for this form
of dignity is that it is an inherent worth held by all members of the human species. A number of writers argue that dignity is held equally by all humans regardless of other faculties (Kass 2008; Nordenfelt 2004; Pullman 1999). This is commonly referred to as ‘basic’ human dignity or Menschenwürde. Describing this type of dignity, Gallagher (2004: 590) states:

‘People have this dignity or worth regardless of their levels of competence, consciousness or autonomy, or their ability to reciprocate in human relationships. They have this dignity purely because they are human.’

This form of dignity is inclusive of all humans and is stable and enduring (Gallagher 2004). As such, it appears the ideal candidate to establish dignity for people with dementia and ground an ethical model. Haugan (2010) believes that it is a relatively uncontroversial notion that dignity applies to all human beings. Pullman (1999) argues that when autonomy is lost, others can still honour this enduring basic human dignity by intervening paternalistically.

Yet, Pullman (1999) does not outline what constitutes this basic human dignity or how it ought to be honoured. Without further explanation, it begs the question of what the source of this dignity is. As Cochrane (2010: 236) puts it

‘If all human beings possess dignity – this extraordinary moral worth – we need some explanation of what it is about the species Homo sapiens that makes them so deserving.’

This problem is not lost on all promoters of the concept. For example, Kass states (2008: 315-6)

‘... asserting that we all have “equal dignity” does not, by itself, make it so. Mere assertion will not convince the skeptic nor refute the deniers of human dignity.’

Such sceptics may raise the objection of speciesism (Singer 2009) which states that valuing human beings just because they are human is an empty and prejudiced notion if no further argument is offered. As discussed in Chapter 3 (3.4.3), the challenge is that by appealing to the attribute of being a particular species as a source of value discriminates arbitrarily against other species without giving further reasons why this biological difference is significant.
Kass (2008) wishes to point out what it is about human beings in particular that is special. He suggests that it is our psychological ability to respond to the limits of our embodiment that provides us with our humanity.

'It is a [truly human] life that will use our awareness of need, limitation, and mortality to craft a way of being that has engagement, depth, beauty, virtue, and meaning—not despite our embodiment but because of it.' (Kass 2008: 326)

Yet, not every human being is in a situation where they are able to 'craft a way of being' and arguably people with severe dementia would not be able to do this. As discussed above, Kass appears to fall back on the notion that human beings have special 'god-like' psychological properties of reason, freedom, judgment, and moral concern. (Kass 2008). Ultimately, Kass’s view is very close to the views of philosophers who link moral worth to autonomy.

Another approach to ‘basic’ human dignity comes from Nordenfelt. He prefers the term Menschenwürde and describes it as ‘...a kind of dignity that we all as humans have, or are assumed to have, just because we are humans.’ (Nordenfelt 2004:77). Yet, immediately there is some uncertainty here. It is one thing to suggest that human beings have such a dignity; it is something else to say that they are assumed to have it. Though later, Nordenfelt confirms that 'Menschenwürde is once and for all fixed and it is the same for all people.' (Nordenfelt 2004: 79)

Of particular concern here is how Nordenfelt describes the ground for the Menschenwürde, which he links to the following capacities:

‘The first is the human being's consciousness and ability to think, i.e. his or her reason. This includes the power of self-consciousness. Human beings can reflect upon themselves. Second, human beings are different from other creatures in the world through not being fixed. Human beings are free to decide their own way of life.... This is the third element in human dignity, viz. autonomy, most clearly explicated by Kant.’ (Nordenfelt 2004: 78)

As discussed above, the psychological factors of self-consciousness, reflection, reason and autonomy (particularly Kantian autonomy) start to fall away as dementia develops. Nordenfelt appears to not see a problem with Menschenwürde applying to all human beings yet being grounded by a property that is not held by all of them. In fact, he repeats the same reasoning in later work (Nordenfelt 2009: 39)
One possible explanation relates to how Nordenfelt understands Menschenwürde. In describing its ground, he asks the question:

‘What is it about humans as a species that gives them a high dignity?’ (Nordenfelt 2004: p78)

This suggests an important difference between describing the dignity of an *individual* human being and the *species* as a whole. The argument could be run that although an individual no longer has the appropriate *psychological* capacities for Menschenwürde, they are *biologically* human so can still have the status held by human beings as a species as a whole. Such reasoning could also be used to salvage Kass’s account above, not to mention the psychological view of personhood discussed in the previous chapter.

Yet, there are some difficulties with this view. Firstly, it appears to be an equivocation to ground dignity in psychological properties but then grant it to a biological category. Secondly, biological entities that are part of the human species vary greatly, from an embryo to a fully developed adult. Yet, such a view would have to apply an equal dignity to all of these beings. Furthermore, as Cochrane (2010) points out, it is not clear what the obligations generated by such an account of dignity actually are. Put in concrete terms, if the view is held that certain psychological capacities ground dignity then what is the correct response if faced with a human being who is judged not to have them? It is possible to say that certain psychological capacities ground the status of all human beings. Yet, in a caring situation it is problematic (at best) to respond to a particular *individual* in terms of respecting a dignity based in certain psychological attributes of the species, if that capability is believed to be absent for individual.

Similar concerns about concrete application can be expressed about religious views based on sacredness and humans being made in God’s image. This line of thinking is found in Kass’s work along with others such as Gelernter (2008) and Kraynak (2008).

Religious views by their nature are hard to refute. People are free to believe that dignity is God given. However, others are equally free to believe it is not. Similarly, in these situations how members of the human species are to be treated may be reliant on what has been instructed by religious texts. A group of people could agree that a certain religious code provides adequate guidance for dementia care; yet others may easily dispute this assertion if no further argument is given. As a result, such views would not
fulfil the overall aim of this thesis which is to establish the best philosophical approach to ground an ethical model for dementia care.

It is worth noting at this point, that a similar argument can apply to personhood. People are free to call any entity they wish a person. This could include all humans but also pets, rivers, mountains etc. The point, however, is that in order to be meaningful, the term must have an adequate grounding and produce a response that is reasonable as a result.

4.5.2 LIVING A DIGNIFIED EXISTENCE AS A HUMAN BEING WITH DEMENTIA

It has proved difficult to establish a basis for human dignity or Menschenwürde for people with dementia without relying on properties that may be absent when the condition is severe. Basing individuals’ dignity on inherent worth, grounded by the properties of their species as a whole, appears incoherent. However, there may be another avenue to follow. As discussed in the introduction, the notion of a dignified existence for a human being in general is one that people can relate to. This section will consider how we might live a dignified existence as a human being with dementia.

By using the term ‘dignified existence as a human being’, this proposes that the dignity of the species as a whole contains certain objective ideals associated with it towards which everyone should either personally strive or be helped to attain. Cochrane (2010) refers to a similar concept when dignity is understood as species integrity.

This concept is also related to the notion of human flourishing which Nussbaum connects with such an understanding of dignity (Cochrane 2010). Nussbaum believes that people's dignity is promoted by allowing them to develop their capabilities in order to flourish as full human beings. These capabilities include things such as health, freedom of movement, security, control over one's environment, using the senses in a 'truly human way' and '[b]eing able to form a conception of the good' (Nussbaum 2008: 377-378). Yet, there is the seemingly obvious problem that people’s capabilities are reduced when they get dementia. In order to try and include people with cognitive impairment Nussbaum states that a single capability (such as practical reasoning) should not be used to ascribe human dignity. However, there is a lack of guidance on which of the capabilities might be necessary or sufficient.
To try and get a clearer view about what a dignified existence might mean, it is worth considering some examples. The first is to consider again the example from Gallagher (2004) who was told by a woman that dignity for her was having a saucer with her cup. What is it about providing someone with a saucer under their cup that might enable them to flourish as a dignified human being? It could be that the basic animal process of drinking a liquid needs certain elements in order to show that it is part of a dignified human existence. This may sound contrived. However, to illustrate, it is worth considering the extreme opposite: perhaps where tea has to be drunk by patients from a spout in the wall. This fictitious scenario is likely to be judged as undignifying for all human beings. After all, this is how gerbils behave; it is not how humans behave. So there is a point where the tea is served in a way that is undignifying for humans in general suggesting an objective species norm rather than just a subjective preference.

To extend the example further, the woman concerned may start to lose mental capacity resulting in a radical change in her preferences. In this new state, the woman will now only agree to eat her food off a plate on the floor. This causes concern for people witnessing this as they think that the woman should not be allowed to eat in this manner.

Both of these alternative eating scenarios, from a plate on the floor or through a tube, can be viewed as undignified in terms of a previously stated subjective dignity preference to have a saucer with her cup. Interest here is focused on what the implications are for being a dignified human being in general. Perhaps, being a dignified and flourishing human being involves eating and drinking in a certain way and therefore this needs to be promoted by people caring for those with dementia.

Shaub (2008:383) seeks to show the relevance of this for some dignity theorists when she says that ‘Feeding can become dining and procreation can become family life.’ However, it equally seems that this is about cultural relativism. In some Asian cultures, it is considered perfectly normal to eat with your hands while sitting on the floor. The sense of repugnance that may be felt watching someone eat in this way may easily be related to cultural preferences rather than an objective notion about what people need in order to flourish as human beings. It also seems likely that the sight of a tube
delivering food is likely to be more readily accepted in some cultural contexts than others.

4.6 THE FUNCTION OF CULTURE IN DIGNITY

To clarify the function of culture in dignity, a final example is proposed. Recall the example, raised in the introduction (1.6.3), of a professor, who has a long and distinguished academic career behind her. Now in an advanced state of dementia she lives in a nursing home. The professor has little recollection of her previous role and shows only a fleeting interest in her area of research. At times she gets frustrated with other people in the home. It has been found that providing a doll to comfort her, which she believes is a baby, can reduce her distress. While holding the doll, the professor can be heard by others in the home interacting with the doll using baby talk.

Though, there is evidence to suggest that using dolls in this way can be effective for managing agitation for people with dementia (Mitchell and O’Donnell 2013), doll therapy is considered controversial for two main reasons. Firstly, it can be perceived that giving someone a doll treats them in a child-like way and is therefore infantilising (Mitchell & Templeton 2014). This follows from arguments made over a number of years that it is important for older adults to have age-appropriate experiences (eg. Salari 2002)

Secondly, when using dolls in this way, people with dementia are not corrected when they perceive the doll as a baby and are therefore being deceived (Andrew 2006). Yet, Andrew (2006) goes on to argue that despite these concerns, doll therapy actually maintains dignity more than the alternative methods of managing agitation such as using chemical or physical restraint, and it also promotes dignity by providing an opportunity to ‘...give care rather than receive it.’ (Andrew 2006: 419). It appears that Andrew does not deny that there is something undignifying about giving an adult a doll that they believe is a baby. Yet, she believes that there are other elements of the process that are dignifying and the alternative of using restraint is worse overall for the dignity of the individual.
When analysing the example above, it is important to separate out what might be undignifying for any human being and what might be undignifying for the professor in particular.

Firstly, the arguments outlined above that this practice is infantilising and deceiving suggests that there is risk that dignity can be disrespected or undermined for any adult human being in this situation. It would seem that an adult human being cannot flourish if behaving in a seemingly child-like way and this is further hindered by leaving someone in a state of ignorance about the true nature of the doll.

Cultural context may also be important here. It may well be acceptable for someone with dementia to interact with a doll in such a way in the context of a nursing home; whereas it would not be for someone to do so in a public place, or as a professor in their workplace. On the other hand, it could be argued that there are certain things that should remain as similar to mainstream society as possible even in a nursing home context. For example, people may expect adults with dementia to be dressed in the similar manner to how adults of that age would dress at home.

It seems that expectations of the society that surrounds the individual with dementia is a key factor for dignity here. This idea is reflected in the followed personal view of Kathleen Morgan (2011: 281-282) who has a diagnosis of dementia:

‘Dignity is being treated like any other woman. I still like the same things I used to – fashion, style, babies, the things I can’t do, I still like. Dignity is being dressed right. Appearance is everything because that is what we are all judged on. We must look the best we can to be accepted (for as long as we can) by society.’

Morgan is clear about the link between the judgement of others and having dignity. Though it is a personal view, Morgan’s language suggests that ‘being treated like any other woman’ and having our appearance judged favourably are essential elements of dignity for everyone. Nonetheless, notions such as being ‘dressed right’ are clearly linked to the culture in which Morgan or anyone else may find themselves.

This leaves the difference that might be made by the woman in the example being a professor. The inclusion of this is more than a rhetorical flourish. It is argued by Nordenfelt that dignity can be obtained by people having certain standing in society. He refers to this as dignity of merit and it is often provided by an older person’s past
employment (Nordenfelt 2004; 2009). Wainwright and Gallagher (2008) argue that dignity of merit actually relies on another of Nordenfelt’s categories: the dignity of moral stature. In this example, this would mean that the professor’s dignity does not just relate to her having been a professor but also on her having carried out that role in a manner judged appropriate.

Accepting Gallagher and Wainwright’s interpretation still leads to people such as the professor having a higher dignity based on their societal status, just as long as they live up to the status of their role. Assuming this is the case in the current example, the relevant point is that it seems to follow that it is easier to find oneself in an undignifying situation having been in a position of high moral standing. This is because the threshold of an acceptable level of dignity is higher. Put colloquially, there is the potential for a larger fall from grace.

However, as highlighted by Wainwright and Gallagher (2008), there is also a strong argument that status of this kind should not make a difference to sort of care that the individual receives. This suggests that the care response should only be based on the dignity which is shared by all human beings. In light of this, the fact the woman concerned is a professor is merely a red herring in terms of making the doll therapy more undignifying.

Ultimately, whether the woman in the scenario is of especially high standing in society or not, the dignity that is associated with her is based on the expectations of that society. In the discussion on subjective forms of dignity earlier, individual dignity expectations were found to be associated with personal autonomy. This time, expectations are based in the culture of the society around the person. These expectations may differ depending on both the standing of the individual in that society or on what that particular society expects for human beings in general.

Support for the idea that cultural expectations of society can be a source of dignity has been found in a mixed method empirical study by Edlund et al (2013). They suggest that dignity has a relative component which is highly changeable depending on culture in a society and all the norms and rules that it involves. Though, it is worth noting that Edlund et al (2013: 855) also propose that human beings have absolute dignity, which is gained by creation and cannot be taken away or even ‘called into question’. This implies
a religious view and such positions have already been tackled above, so will not be pursued further here.

A final example to illustrate the importance of cultural acceptance in dignity is when people’s physical condition deteriorates towards death. In this situation, it appears that certain cultures in society have a need to maintain dignity by maintaining appearance not just through actions like dressing appropriately but also through keeping the human body contained and clean. Building on the work of Lawton (1998), Komaromy (2005) describes how staff in nursing homes feel the need to contain people’s ‘leaking bodies’ in order to make them acceptable for those around them.

So, it appears that a view of what is acceptable for human beings within a particular culture brings certain expectations for dignifying care. However, the aim of this section was to look for objective forms of dignity. The problem of relying heavily on the view of society brings a similar problem to that which was found with Kitwood’s social constructivist view of personhood discussed in the previous chapter.

Recall, social constructivism sees the human self and its personhood as being constructed by society rather than solely existing due to the individual’s mental processes (Hughes 2011a). This was found to be unreliable as there is nothing in this idea that stops societies deconstructing personhood for people with dementia. If dignity expectations have similar causation then it seems plausible that people with dementia could be treated variably depending on what dignity is seen to be. This could lead to a situation where people with dementia are unable to meet the expectations set.

Returning to Morgan (2011:282), her perspective suggests that this is a consideration for her:

‘In reality there is no dignity in dementia. If we are not careful, we can become so sensitive to loss of dignity that we see loss where there is none. We all view dignity and what affronts it differently. This must make it tricky to put dignity into training; can you train dignity?’

So this variability in how people view dignity in society appears to leave open a risk of equivocal judgements about how dignity might be honoured for people with dementia or deciding whether it has been lost. In conclusion, it can be seen that if dignity is no
longer dependant on inherent properties of either the individual or the species, the concept then becomes highly susceptible to cultural context.

4.7 SUMMING UP DIGNITY

As Morgan (2011) states above, it is challenging to get to the bottom of what dignity is. In this vein, it is worth reiterating the definition quoted near the beginning of this chapter from Matiti's research:

‘Patient dignity is the fulfilment of patients’ expectations in terms of values within each patient’s perceptual adjustment level, taking into account the hospital environment.’ (Matiti 2002, cited in Matiti and Baillie 20: 14)

Initially this seemed an overly subjective and fluid definition of the concept. Yet attempts to ground it more solidly on an objective footing (in a way that is not reliant on autonomy) have proved problematic. The type of dignity referred to as ‘basic’ was found either to rely on a seemingly unjustifiable preference for the human species or to rely (once again) on attributes based in autonomy that may be absent for people with dementia. The notion that there is a dignified human existence towards which we all should strive initially seemed promising. However, on closer investigation this understanding of dignity is highly dependent on societal norms. This means that people with dementia could be treated variably depending on how dignity is seen by the culture which surrounds them.

As outlined at the beginning of this chapter, dignity, despite being variously understood, is something that matters to people. The empirical literature continues to provide information on how people understand dignity in various contexts. The importance of a dialectical relationship between this empirical work and the conceptual work has been accepted.

Despite a lack of objective definition, it has been suggested that care providers are still able to act with an ‘intuitive understanding’ (Seedhouse and Gallagher 2002: 369) in order to honour what they see as dignity for people in their care. The source of such intuitions is worthy of further investigation, and this may offer a way for a spiritual perspective to be incorporated that is less open to challenge than in the examples outlined above.
The remainder of the chapter will explore whether philosophical approaches using an existential perspective might bring us closer to understanding the source of such intuitions.

4.8 THE RELEVANCE OF AN EXISTENTIALIST PERSPECTIVE

There are numerous existentialist approaches that might inform an ethical model for dementia care. The focus here is on two existentialists Martin Buber and Emmanuel Levinas who have been particularly influential in the foundation of relational ethics and in doing so have also drawn on spirituality in their work (Buber 1959; Davis 1996). Notably the 1923 work entitled *I and Thou* from Buber (1959) heavily influenced Kitwood’s person-centred care (Kitwood 1997). The work of Buber and Levinas taken together are understood to be a major influence in the formation of the perspective of ‘personalism’ as applied in healthcare ethics in general (Schotsmans 1999) and also to dementia care in particular (Baldwin 2011).

Another relevant existentialist thinker is Maurice Merleau-Ponty. In his 1945 work *Phenomenology of Perception* (2012), he argued that the role of our body in understanding experience is central. Recall that this philosophy along with the work of Heidegger provides a philosophical grounding to the Situated Embodied Agent (SEA) view of the person discussed in the last chapter (Hughes 2013; 2011a). Though Merleau-Ponty’s work does not draw on spiritual themes, Hughes sees the broader notion of spirituality as being a ‘non-negotiable’ element of understanding the person (Hughes 2011b: 204). There is arguably a trend which seeks to bring together existentialist and spiritual ideas in discussions of dementia care.

As well as being an existentialist, Merleau-Ponty is part of what is described by Smith (2013) as the historical movement of phenomenology. Levinas, mentioned above, is also a relevant figure here. Though broadly part of this movement, Levinas was highly critical of its key figures moving it away from what he saw as its solitary tendencies in order to develop his concept of the Other (Davis 1996). The relevance here is in considering the response the Other generates in the person providing care for someone with dementia.
This section will revisit the ideas that stem from the writing of Merleau-Ponty, Buber and Levinas in a way that marks a break philosophically from what has gone before. Rather than theorising about concepts or attempting to find the objective truth from empirical methods, existentialism seeks answers from the concrete experience of our personal situation (Langer 1989). The overarching aim of this chapter has been to get at what it is that people understand by the experience of caring for another human being and how this understanding might ground an ethical model for dementia care. This section will now investigate whether an existential approach may bring answers where the previous investigation has left questions.

4.8.1 THE BODY AS A SOURCE OF INTUITION

This chapter has examined being a person more broadly than in the previous ones by basing it in the notion of humanness. Part of this is an appreciation that people with dementia, along with those who care for them, are embodied human beings (Hughes 2013; 2011a). Focussing on how a sense of self is manifested in the body is a central part of recent thinking in dementia care (Downs 2013). Being a person in the sense that we inhabit a human body is something that we all share. Recall the statement of Hughes (2008:129) from that the previous chapter (3.6.2):

‘...people with dementia, because we all occupy the same human worldly groove, remain persons even in the severer stages of their disease. The requirement that we should be person-centred, therefore, stems from our being human.’

It was argued there that this focus on 'being human' resulted in a position vulnerable to speciesism. However, a more existentialist interpretation is possible, and based on his other work (Hughes 2013; 2011a) this is probably closer to what Hughes intended. An existentialist interpretation would focus on the experience of being human in this world, on which we all can draw.

So what does this shared experience produce ethically for dementia care? A criticism raised against Hughes in the last chapter was that despite his view providing a sound description of what it is to be human, it was unclear how this could be translated into a basis for an ethical model when personhood was at its centre. Looking beyond personhood as a moral status, this chapter has raised the possibility that responding to someone as a person might be a richer and more intuitive notion rather than just
recognising that someone has certain morally relevant attributes and then respecting them. This notion of the intuitive appears to offer a way in. As Hughes (2013: 356) puts it:

‘...the foundations for good care emphasise the importance of knowing the people we care for in as holistic a fashion as possible. We are back to ‘being with’ as a priority before ‘doing to’. And we are back to the importance of the intuitive, the expert clinical judgement based on feelings akin to an aesthetic sense of what is right.’

So it appears that for Hughes the right thing to do is based on a mixture of aesthetic and reasoned judgement. Rather than responding solely to reason, it is about care providers feeling what’s right.

This vein of thought reflects the philosophical shift outlined above. The aim is no longer to argue solely in terms of obligations generated by the features of the human individual being cared for. Instead, care providers must also use their ability to feel, making akin to aesthetic judgements rather than merely drawing on their ability to reason based on the facts presented. It is worth noting that the relegation of reason in ethics and an increasing role for feeling (or sentiment) also reflects the classical philosophical work of Hume (1751/1998) and this important theme will be returned to in Chapter 6 (6.2.1).

A full assessment of the works of Hume, Wittgenstein, Merleau-Ponty and others mentioned above is beyond the scope of this thesis. A search for an ethical model for dementia care can develop, without much digression, into a full assessment of what makes a viable theory of ethics overall. The focus here will be kept on how these ideas can be used for the purpose here of grounding an ethical model.

It seems to fair to accept that the human experience of being embodied, which includes having feelings and emotion can bring wisdom in the form of an intuitive feel for the care needs of another human being. Encouraging care providers to be more aware of this as a resource seems a sensible strategy. This may well promote a sense of connection and collaboration in how people are cared for. However, is it sufficient when used as a way to respond to concrete ethical dilemmas? Hughes certainly thinks so when he states:
‘In the end, good decisions will be made when those involved have had the courage to look with some intensity at the face of the Other; when encounters, however brief, are at the level of the soul.’ (Hughes 2011a: 264)

Yet, if the suggestion is that all people have to do is to look someone in the eye and they will intuitively know the right thing to do, then this may be judged overly optimistic by some. For Hughes, this encounter produces judgements that are aesthetic and therefore not describable in everyday language. Nonetheless, it is possible that from this a less rigid, but still viable ethical model, could be constructed and this will be returned to in later chapters.

4.9 RESPONDING TO THE OTHER

4.9.1 I-THOU RELATIONSHIPS

As discussed, the influential work on person centred care by Tom Kitwood (1997) has its philosophical roots in the work of Martin Buber. The crux of Buber’s work is that the life of human beings involves either experiencing other entities as objects, which is referred to as I-It; or being in relation with them, which is referred to as I-Thou (Buber 1959).

For Kitwood, it is empathy that makes it possible to respond to someone as Thou. Furthermore, the promotion of I-Thou relationships with people with dementia is an essential part of maintaining personhood, as Kitwood defines it. However, as discussed in Chapter 3 (3.6.1), Kitwood’s view relies on personhood being bestowed by one human being on another. The worry outlined in Chapter 3 is that such a mechanism is highly vulnerable to being influenced by the social constructivist forces that Kitwood had set out to counteract.

The question here is whether in this chapter, following the reorientation of personhood away from being understood strictly as moral status, a reassessment of Kitwood’s view is possible. Kitwood makes the following plea for people to accept the foundation of personhood in Buber’s terms along with the assumptions that lie behind the view:

‘There is, of course, no way of proving – either through observation or experiment – whether Buber’s fundamental assertions are true or false. Any attempt to do so would make them trivial, and statements that appeal through their poetic power would lose their meaning…. Before any kind of inquiry can get
under way in a discipline that draws on evidence, assumptions have to be made... These assumptions are metaphysical beyond the possibility of testing.’ (Kitwood 1997: 12) [my emphasis]

It is worth noting, firstly, the reference to an appeal from poetic power. This suggests a similar view to Hughes that judgements can be made *aesthetically* and are therefore not describable in everyday language. Kitwood is suggesting that any attempt to try and analyse Buber’s fundamental assumptions into their core elements would result in a loss of meaning. Secondly, Kitwood does not elaborate fully on what he means by ‘metaphysical assumptions’, though there is reference to these assumptions being religious in their nature.

In short this all implies that there are certain ideas about being human that need to be believed for Buber’s view to be convincing. The main one is that *relating* is the source of our link to what is truly valuable or divine. This is plausible. However, basing the idea on these metaphysical assumptions leads to a less solid ground for an ethical model. There is no answer to the simple challenge that although relationships are part of caring, they are not *in themselves* the source of value on which ethical conduct is based. In other words, it is not the relationship itself that carries the moral weight; it is the human beings (and their thoughts and feelings) that are ethically important. If the focus is solely on relationships, then it also raises the question whether this means that a solitary human has less moral weight than one in relation. In response to this, Buber’s original line of thinking suggests that even a solitary human still has a relationship with God.

Baldwin (2011) criticises Kitwood for not fully appreciating that Buber’s I-Thou formulation is ultimately founded on this relationship between the person and God. So, it seems that there is an element of religious faith required for these metaphysical assumptions even though they are hidden in Kitwood’s more humanistic interpretation. As a matter of faith, there is the choice to believe these or not. If these assumptions are not believed, then there is little progress in this regard from the conclusion reached in Chapter 3 on Kitwood’s account of personhood. This concluded that Kitwood’s reliance on others *bestowing* personhood is vulnerable to challenge as it is does not provide an argument that obligates such a moral status to be bestowed. There seems to be little in the way of further argument to be found by drawing on Buber.
Though, it is worth noting further arguments to support Kitwood multi-faceted work can still be found. As pointed out, Kitwood discusses the importance of the care provider developing themselves as human being with an empathic orientation towards people with dementia. The importance of development of character and receptivity to emotion in the care provider with be discussed in depth in Chapters 5 (5.5) and Chapter 6 (6.2.3). Finally, there may well be consequentialist reasons for bestowing personhood in sense understood by Kitwood. Consequentialism will be explored in Chapter 7 (7.6).

4.9.2 THE OTHER

Baldwin (2011) favours the existentialist philosophy of Levinas as a basis for a care ethic. This manages to avoid the element of faith that is seemingly required for Buber’s vision. The important element in Levinas’s work for Baldwin is the response that is generated by the face (le visage) of the Other. Levinas is critical of Buber’s formulation as it implies an over-familiarity with the Other (Davis 1996). For Levinas, it is the failure to fully understand the Other that makes them radical and generates our ethical response. As Davis (1996: 48) puts it:

‘...the Other makes me realize that I share the world, that it is not my unique possession, and I do not like this realization. My power and freedom are put into question. Such a situation is ethical because a lot depends on how I respond.’

The Other makes an appeal through their very existence. Yet, it needs to be clarified how this call should be answered. How should care providers respond to such a call generated by their connection with people with dementia?

It is proposed here that Nagel (1986: 179), though not an existentialist, offers a ‘moral phenomenology’ that may be useful. The relevant part of Nagel’s work is that which discusses the perspective or ‘point of view’ of the individual who is being acted upon. In our case this would be in a caring context, though Nagel is concerned with the ethics of doing harm to an individual for a greater good. As such, Nagel argues that the perspective of the ‘victim’ brings strong moral constraints on the behaviour of those acting on them. When in close contact with someone else they can make a direct appeal not to be harmed in a way that is stronger than the reasons that might be given against the harm if it was done impersonally.
The relevance of Nagel’s perspective in a caring context is the individual we are caring for might make a similar appeal. This is not to suggest that recipients of care are victims. The grounding of the appeal rather than being an overt “do not harm me” as expressed by the potential victim in Nagel’s work may instead be expressed more subtly by the vulnerability of the human being in more general terms. As pointed out by Sellman (2011; 2005) all human beings are vulnerable due to the self-evident fact that we are not immune to everyday risks. Sellman goes on to suggest that vulnerability is a matter of degree. If our capacities for protecting ourselves from these risks are sufficiently reduced, such as may be the case with dementia, then we can be considered ‘more-than-ordinarily’ vulnerable.

Arguably, it is the perceived vulnerability of the Other that demands that we limit our power; it is this that generates a caring response to our fellow human beings. The decline of cognitive powers is likely to bring with it a particular vulnerability. If compassion is generated in this way, then witnessing a fellow human being with such a decline actually heightens our compassionate response. The human being, though losing cognition, is more able to engender this ethical response from the care provider.

If this line of thinking is accepted, then this marks another shift in philosophical thinking. The existential-phenomenological approach gives a window into the world of how we relate to one another. However, in order to realise this as an ethical vision we need to respond with wisdom to a vulnerable and dependent other. This calls for a broadening of the discussion to explore virtue ethics, ethics of care and the role of emotion in the caring encounter.

4.10 CONCLUSION

The chapter began with the suggestion that few people outside of philosophical circles would defend the notion that a human being is a nonperson. This is particularly the case in a caring context, where to do so may cause offence. So a question was posed asking what people might mean when they say that an individual is a person, if it cannot be established based on psychological capacities. From this it was suggested that people were getting at humanness as the key attribute when using the term person. The aim of the chapter was then set to explore what people understand by the experience of caring
for another human being and whether this might be able to ground an ethical model for
dementia care.

The bulk of the chapter was concerned with the notion of human dignity. This began
with a discussion to clarify if there is a relationship between dignity and autonomy. The
nature of the relationship depends on how each of the terms is understood. A key
distinction is between subjective and objective form of dignity. It was argued that
subjective forms of dignity were closely linked to people's individual autonomous
preferences about how they expect to be seen or treated. As it has been established in
Chapter 2 that some people with dementia lack the ability to form autonomous
preferences, it was decided that exploring dignity as an objective notion was a more
promising avenue.

The exploration of objective forms of dignity began with the assessment of dignity
understood as an inherent worth held by all members of the human species. This is
sometimes referred to as 'basic' human dignity or Menschenwürde. However, the
challenge here was the source of such dignity being based solely on being a member of
the human species. Attempts to justify why human beings are special and warrant such
dignity was found again to rely on psychological attributes that are associated with
autonomy. This left uncertainty as to how human beings should be responded to when
they lack the psychological attributes that grant dignity to the human species as a
whole.

As a result, the discussion moved away from inherent worth onto one of a dignified
existence of human beings in general. Though the intention here was to establish an
objective set of ideals towards which all human strive; in practice it appeared that these
ideals were reliant upon cultural context and the expectations of society. This resulted
in dignity understood this way being highly changeable depending on this context,
leading to the objection that it is socially relative.

Nonetheless, it was put forward that care providers might act with intuition when
honouring dignity. Building on this theme, the latter part of the chapter, examined if
existentialist perspectives might be able to better capture what it is that people
understand by the experience of caring for another human being and how this
understanding might ground an ethical model for dementia care.
Firstly, Hughes’ situated-embodied-agency view was re-examined. Hughes is keen to see the aesthetic nature of making ethical decisions when directly encountering another human being as an intuitive response based in the experience of being an embodied human. This opens some important avenues in terms of an increasing role for feelings in making ethical judgements.

Next, Kitwood’s engagement with Buber’s work on relational ethics was considered. Similarities could be seen with Hughes’ approach as Kitwood also draws on the appeal of the poetic power of Buber’s work. However, deeper investigation found that certain metaphysical assumptions of a spiritual nature had to be accepted before Buber’s view on the value of relationships could be followed.

Finally, the existential encounter with the Other was examined through the phenomenological lens of Levinas and Nagel. It was proposed that in a caring interaction the call of the Other is one that is linked to their inexplicability but also their vulnerability. It was further proposed that an increase in vulnerability brought about by a decline in cognition generates an ethical response in care providers demanding that they limit power. It was then suggested that an ethical model might be founded primarily on this lived experience. Guidance on how to respond to this experience as a care provider is aligned more closely to virtue ethics and the ethics of care.
5 VULNERABILITY AND VIRTUE ETHICS

5.1 INTRODUCTION

The last chapter marked the beginning of a philosophical shift. Rather than establishing the moral status of the individual with dementia as the sole basis of an ethical model for care; instead, the importance of shared humanity and how the care provider might act intuitively in the caring encounter was emphasised.

As the discussion in the last chapter developed, it was suggested that the phenomenological experience of the care provider was of central importance. It was then further suggested that the decline in cognitive power experienced by people with dementia, which created difficulties for ethical views based on moral status, may actually engender a positive ethical reaction from the care provider. The vulnerability and dependence of the fellow human being (or Other) instils the idea that care providers themselves are also vulnerable and dependent on others to a greater or lesser degree in their lifespan. This realisation, though possibly unsettling, may also contain the genesis of a positive caring relationship. It was suggested that the source of an ethical model may be found primarily in this lived experience of the care provider.

This chapter will explore the notion of vulnerability in more depth. This leads the discussion onto how being sensitivity to vulnerability can lead to cultivating virtues that guide the care provider towards good care. Here, the ethical resources drawn on are centred in the character of the care provider and, as such, the focus is on how care providers should be rather than what they ought to do. The aim of a virtue ethics approach in caring is therefore to develop a good character that will be able to respond wisely and sensitively to the everyday challenges of dementia care. This chapter will examine also the role of moral education and exemplars in this process before introducing the key notion of receptivity.

5.2 Responding to Vulnerability

5.2.1 The nature of vulnerability, interdependence and trust

The previous chapter introduced the idea that human beings, by their nature, are vulnerable to risks in everyday life (Sellman 2011; 2005). We are vulnerable to harm
physically by seemingly mundane events such as walking down stairs, travelling in cars, catching a cold. We are also vulnerable emotionally to states such as being saddened, frightened, ashamed or indignant. Psychologically we are vulnerable to events that can make us anxious, develop low self-esteem or feel paranoid. In turn, vulnerabilities in one area can lead to heightened vulnerability in other areas such as economic and social vulnerability (Carel 2009)

These vulnerabilities are a matter of degree and may or may not lead to harm. They will vary both between individuals and throughout our lifespan. We are all vulnerable when newly born but the hope is that we will become increasingly less so as we move to adulthood and develop strategies to protect ourselves from risks.

Though, as we cannot manage all risks, inevitably we also place trust in others. Trust, if appropriately placed (O’Neill 2002a; 2002b), reduces vulnerability. However, trust, if inappropriately placed, increases it. As O’Neill (2002b: 24) points out, ‘[a]ll trust risks disappointment’ and every time we place trust it is not without risk. So, we find ourselves in a situation of risky interdependence as we cannot be fully sure that others will be able to live up to the trust we have placed in them.

For people who value the idea of independence accepting oneself as vulnerable and interdependent in this way may be unsatisfactory. There is a tendency in health care to overemphasise the importance of independence (Nolan et al 2004). In reality, the fact of our interdependence as human beings seems hard to deny. Furthermore, as Kittay (1999: xii) highlights, interdependence is not merely a matter of mutual cooperation between ‘essentially independent persons’; it actually describes the reality that we are all dependent at some points in our lifetime and many of us must care for people who are dependent.

For some, the capacities for protecting themselves from risks are significantly reduced for reasons that are out of the ordinary, such as illness, reduced mental capacity, or unconsciousness. This reduction in the capacity for protection is referred to by Sellman (2011; 2005) as being ‘more-than-ordinarily’ vulnerable. This concept of being more-than-ordinarily vulnerable is clearly relevant here as developing dementia means that people depend more than usual on others in order to be protected from physical, psychological or emotional harm as well as to have positive events brought into their
lives. People in this situation need to either place trust in others or, if unable to conceptualise the need for this trust, then it has to be placed on their behalf.

Kittay (1999) argues that those who are in need of care are vulnerable to the care provider. This is because people who depend on others for care are vulnerable to the actions or inactions of those providing their care. This situates vulnerability in the relationship rather than being a property held by the individual themselves. The care provider, as someone who is in the position to respond, is obligated to meet the needs of the individual, and as such the care recipient is vulnerable to the care provider not meeting these needs. Kittay (1999:55) sees care providers as having ‘vulnerability-responsive obligations’. Though, she adds that the scope of this obligation is limited, as the care provider is also vulnerable and should not be expected to provide care to the point where they are being coerced unjustly.

This additional perspective on vulnerability can be accepted but only in addition to the account above. On its own it fails to capture the point that people do not have to be in a relationship to be vulnerable. It is quite possible to be vulnerable to a risk without someone else being there to respond. However, noting this additional source of vulnerability as being vulnerable to the care provider is useful, as it is possible to be vulnerable to the actions of someone who in a position to help.

Nonetheless, the focus on relationships found in Kittay is indicative of the approach of a number of care ethicists to focus on relationships and, as such, it marks a distinction with a virtue ethics approach that focuses primarily on the character of individuals rather than what they might be obligated to do (Banks and Gallagher 2009). As a result, the question of the ability to respond to vulnerability as a source of obligation is not a major concern in this chapter. Nonetheless the importance of obligation and relationships to care will be assessed in the next chapter (6.2.3) when the discussion moves to the ethics of care approach, and furthermore it will be considered how this might, after all, be aligned to a virtue ethics approach.

For now, the key point is the effect that vulnerability and dependence has on the character of care providers. It will be argued that vulnerability and dependence is not merely something to be accepted as a part of the fragile human condition; it is also has potential to promote positive individual human responses within the context of caring.
One response of particular relevance to vulnerability is compassion. Goetz et al (2010) describe compassion as an emotion which acts as an intuition in assisting with moral judgements, having evolved in response to perceiving unjustified distress.

'It [compassion] closely tracks suffering, responsibility, vulnerability, and other harm-related concerns and serves as an intuition that guides attitudes that seek to remedy unjustified suffering or need.' (Goetz et al 2010: 366)

In their analysis, Goetz et al (2010) describe how perceiving a negative outcome for a victim is the starting point that may lead to compassion. However, interestingly, they propose that there are a number of other possible emotions that may occur in reaction to seeing someone else's misfortune. They argue that if the victim is believed not to be deserving of help then it is not compassion that is felt but anger. They also put forward that if the victim's suffering satisfies a personal goal for the observer then it is happiness or Schadenfreude that is experienced. Finally, they argue that if the victim is felt deserving of help, yet resources are not available, then distress or fear are experienced in the observer rather than compassion.

Goetz et al's (2010) conclusions can be criticised on two levels. Firstly, it suggests that emotions such as compassion, anger and fear are all-or-nothing and mutually exclusive. However, this may not be the case. For example, when faced with a human being who cannot be helped, it seems possible that both compassion and distress could be experienced. Similarly, it seems possible that at least some compassion as well as anger could be felt towards a victim undeserving of help.

Secondly, this account links compassion to actually witnessing a negative outcome. However, as has been outlined above, someone's vulnerability can be seen in terms of their risk of harm and it seems plausible that this can generate a compassionate disposition without actual harm occurring. This point is supported by Dewar (2011), who conducted an observation study of a British medical ward based on the method of appreciative inquiry.

'The findings of my study demonstrate that acts of compassion happen in numerous encounters between patients and staff, staff and staff, and staff and families. In addition people are driven to respond to others in compassionate ways when they recognise vulnerability, not just suffering' (Dewar 2011: 262)
Confirming in later work (Dewar et al 2014: 1740):

‘If we relate compassionate care only to suffering, then we could miss small but significant interactions that are compassionate.’

Dewar focuses on compassionate acts in care, seeing compassion as being intertwined with the actual care provided (Dewar 2011; Dewar et al 2014). For Dewar, vulnerability needs to be noticed, emotion experienced and then a compassionate act carried out. Taking this together, it can be proposed that compassion is a human response both in emotion and action that is generated by vulnerability, which is not necessarily linked to suffering.

Yet, taking a broader moral view, it can be contested whether compassion is a positive response to vulnerability. As pointed out by Nussbaum (1996), Stoic and later Kantian thinking opposes compassion, seeing it as equivalent to pity. It is thus seen as a position that disrespects the dignity of the individual being pitied and one that merely adds to any suffering being experienced. A Kantian conception (as discussed) sees the human being as possessing a special kind of absolute worth that cannot be exchanged or balanced with anything else (Kant 1996a/1785). In this light, compassion can be seen as a rather patronizing notion when it is directed at fellow free beings who are legislators of the moral law. For Nussbaum (1996:44) the absolute defending or opposing of pity forms the basis of two distinct ways of seeing human beings in society:

‘One sees the human being as both aspiring and vulnerable, both worthy and insecure; the other focuses on dignity alone, seeing in reason a boundless and indestructible worth. One sees a central task of community as the provision of support for basic needs; it brings human beings together through the thought of their common weakness and risk. The other sees a community as a kingdom of free responsible beings, held together by the awe they feel for the worth of reason in one another.’

The distinction drawn here is relevant for understanding ethics in dementia care. As was discussed in the previous chapter (4.3), a Kantian conception of dignity is based on the possession of autonomy, which had already been argued in Chapter 2 to be lacking for people with advanced dementia. So, the view of the human being as both aspiring and worthy but also vulnerable and insecure presents itself as a potentially more inclusive vision for human beings as a whole and more in tune with dementia care.
Nonetheless, Nussbaum (1996) ultimately argues that ethics based on a compassionate response is compatible with moral views, such as Kant’s, which are based on reason. Nussbaum denies that compassion and respect for dignity are mutually exclusive, suggesting it is possible to have compassion or pity for someone while also having respect or awe for how they are responding to the situation. Nussbaum also suggests that compassion actually involves reasoning about the well-being of others. Compassion is not merely taking action blindly based on emotion; it is needed to fully explain ethical conduct.

“...judgment that does not employ the intelligence of compassion in coming to grips with the significance of human suffering is blind and incomplete”
(Nussbaum 1996: 49)

So compassion in the care provider can be viewed as a cognitively-based emotional response to being faced with a human being who is vulnerable. Part of that response would involve an assessment of the capabilities of the individual to respond to their situation. If it allows sufficiently for respect of the care receivers’ ability to respond then it should avoid being patronising, while also not excluding from moral concern those who are unable to reason well for themselves.

Seemingly compassion has a role to play in a broad range of ethical thought. For this chapter, compassion will be put into a virtue ethics perspective.

5.3 FROM VULNERABILITY TO VIRTUE ETHICS

The analysis above focused on vulnerability as result of our potential frailty as human beings. Yet, it is further suggested here that vulnerability can be seen as a positive attribute in its own right; not as something negative that generates a positive response.

It is tentatively suggested here that everyday experiences such as children having a new experience; a person excited about the future; someone appearing puzzled or asleep brings an observable extra quality. These human beings are not being harmed, nor are they at imminent risk of it, yet there is still something that suggests vulnerability and with it an extra positive quality which could also be seen as something beautiful.
So the positive side of vulnerability is more than just the positive emotions that we might develop as a result; part of living richly as human beings is being vulnerable and somehow open. As Carel (2009: 218) puts it:

‘The lesson of vulnerability is not a pessimistic one. Vulnerability also suggests a relationship of openness to the world. Without investing in and caring about transient and vulnerable things, like people, the environment and works of art, we would not be able to flourish. In order to flourish we must let ourselves be vulnerable. To be able to love and care about other people and things outside ourselves is to make ourselves vulnerable. But this vulnerability is also the gate to creativity and flourishing.

So this gestures to another way of linking vulnerability and virtue. It is not just that we might care for vulnerable people but we must allow vulnerability in ourselves in order that we can develop our character. Seemingly care is a particularly valuable opportunity to develop virtue as it allows for an engagement with people who are more-than-ordinarily vulnerable as well as to explore vulnerabilities in ourselves (Sellman 2011; Carel 2009).

The following quote from MacIntyre (1999: 5) further illustrates the point:

‘...the virtues that we need, if we are to develop from our initial animal condition into that of independent rational agents, and the virtues that we need, if we are to confront and respond to vulnerability and disability both in ourselves and in others, belong to one and the same set of virtues, the distinctive virtues of dependent, rational animals, whose dependence, rationality and animality have to be understood in relationship to each other.’

However, virtues and virtue ethics are distinct. It is necessary to now explore virtue ethics as an ethical theory in more depth.

5.4 VIRTUE ETHICS

5.4.1 SCOPE AND FOCUS

A virtue ethics approach requires the care provider not merely to ask what ought I to do in a particular situation but to consider primarily the question of how can I be a virtuous individual (Banks and Gallagher 2009; Tuckett 1998; Slote 1997).
These two questions are compatible as virtue ethics can provide guidance for action as part of the overall aim of character development (Armstrong 2006). As Hursthouse (2003) argues, virtue ethics is concerned with the actions that a virtuous character would perform; the same as deontology is concerned with actions obligated or prohibited by broader principles, or consequentialism is concerned with actions that promotes the best consequences. Nonetheless, a virtue ethics approach does not see ethical dilemmas in a detached manner as problems that require solutions, but focuses primarily on character development through direct involvement.

The key element of the proposal here is that a good character is central in providing ethical care. It is possible for two people to perform the same action. One could do so out of a sense of duty, without being motivated to do so. The other is motivated to perform the action from a sense of virtue, even though they do not believe there is a duty to perform the action. Even though the outcome may appear the same, only the latter is considered worthy of a good character from a virtue ethics perspective (Hursthouse 2013).

This distinction is recognised by Beauchamp and Childress (2013: 32) who state that someone is ‘morally incoherent’ if they perform right actions without having the corresponding virtuous motivation. As authors of a prominent principlist framework in health care ethics, it is interesting that they also make the following assertion.

‘Although principles and virtues are different and taught differently, virtues are no less important in the moral life.’ (Beauchamp and Childress 2013: 30)

So there are some sound reasons to see virtues as a prominent aspect of ethical decision making in providing care. For the purpose of this thesis, a virtue ethics approach to an ethical model for dementia care seemingly has the advantage of making a break from the idea that the presence of certain capabilities of the individual receiving care are of primary importance when making ethical decisions.

The idea that good character is central has a strong history in nursing in particular and has recently experienced a revival of interest (Lamb and Storch 2013; Sellman 2011). Though, the idea that virtue ethics can provide a useful grounding for nursing ethics has been disputed. Holland (2010:153) argues that although virtue ethics may provide a suitable approach for the personal moral life, it should not be extended to the
professional sphere as it makes no sense to declare an aim to develop in terms of a 'nursing nature'. As Holland (2010:153) states:

‘In sum, virtue ethics is an approach to personal morality grounded in a teleological conception of human nature; its applicability to a professional context, such as nursing is, therefore, obviously questionable.’

However, it may not be as questionable as Holland asserts as there is an important rebuttal to his main point. Virtue ethics, by its very nature, does not separate the human being from their role. As pointed out by Putnam (2012: 143) in response to Holland:

‘Virtue ethicists assume that a human life is a whole and that the virtuous individual manifests his or her character traits to different situations, personal as well as ‘professional’.’

In response to this, Holland (2012) remains concerned that this strategy will remove an important distinction between professional and personal ethics. Though, seemingly, Putnam is not worried about retaining this distinction at all. Instead he goes to some lengths to point out that why this distinction is inappropriate by arguing that we should not have differing ethical standards for our personal and professional life.

This point is important here, both as a defence of virtue ethics in dementia care but also as a defence to overall the strategy of this thesis, which aims to construct an ethical model for anyone providing care to someone with dementia. The underlying idea is that the professional / personal division is not one that requires differing ethical approaches. After all, the division between personal and professional is not absolute. Professionals are expected to behave with good character in both their professional and personal lives (Nursing and Midwifery Council 2008; General Medical Council 2013).

It is accepted here that there may be additional demands on professionals relating to their specific role over that of a non-professional carer. However, there may be additional moral demands also for non-professional carers, such as the responsibilities that come with being a family member. It is also accepted that someone from a professional background is likely to have started to cultivate the necessary character traits as part of their education and working life. Nonetheless, it is possible for a model to be of use for anyone involved in ethically challenging dementia care situations as long
as it is flexible enough to account for the differing moral requirements that individual care providers and care receivers might have.

5.4.2 VIRTUES FOR CARE PROVIDERS

It has been suggested above that trustworthiness and compassion are virtues that might arise in response to vulnerability. A number of other virtues have been suggested by scholars investigating which might be most appropriate for people in caring roles (Banks and Gallagher 2009). These have tended to be aimed at professional groups.

For health and social care professionals, Banks and Gallagher (2009) select courage, professional wisdom, respectfulness, care, justice and integrity, along with trustworthiness. With a focus on helping relationships, Armstrong (2006:120) selects ‘...compassion (including benevolence or kindness), courage, respectfulness, patience, tolerance, justice, trustworthiness, and honesty.’ In discussing psychiatric nursing, McKie and Swinton (2000:38-41) have produced a similar list stating that care, friendship, trust, honesty, faithfulness, commitment, patience, justice, respect, insight and empathy are all virtues to be ‘learned’ as part of a hybrid framework that also draws on deontology. Finally, Sellman identifies the historical value of Nightingale’s virtues of obedience, punctuality and observation (Sellman 1997); but in a more recent account highlights core virtues necessary for nursing as justice, honesty and courage, with trustworthiness and open-mindedness also being of central importance (Sellman 2011).

It is worth noting that members of this list of virtues fall on both sides of the traditional distinction of self-regarding and other-regarding virtues. By this distinction, courage would be described as a self-regarding virtue – a virtue that largely benefits the holder of the virtue, whereas compassion would be other-regarding. However, closer examination helps to dissolve such a distinction. A virtue such as courage on closer scrutiny can be seen as a mixed virtue (Slote 2001). There are benefits for the holder but clearly some courageous acts regard others too. It can be concluded, as it has elsewhere (Hursthouse 2013), that this distinction is not required.

In a caring context, courage of the care provider is beneficial for others as it enables ethical care to be provided in challenging circumstances (Banks and Gallagher 2009). These circumstances may be unavoidable such as the courage that is needed to deliver
bad news to a loved one. However, Hamric et al (2015) point out that courage is sometimes required in order to respond to sociopolitical and institutional barriers. In this situation they argue that rather than expecting courage, instead the focus should be on alleviating the conditions that are causing the challenge. In other words, an expectation of courage should not be used as a way of maintaining oppressive sociopolitical conditions. This theme will be returned to in the next chapter when sociopolitical basis of ethical care is examined.

Overall, it can be asserted with some confidence that a range of virtues such as courage, patience, compassion, commitment, trustworthiness, and so on, are good dispositions to have when caring for someone with dementia. Yet, as Holland (2010) points out, merely making a list of positive character traits is not sufficient to demonstrate that virtue ethics is being employed. For example, merely saying that care providers should be compassionate appears to be of little help in helping people through the challenging scenarios that are met with some regularly in everyday care.

To illustrate, let us return again to the example from Schermer (2007). Recall, that this involved a woman (we have called Jane) with dementia banging on the door of a locked ward begging to be let out to collect her long since grown-up children from school. It was found by people caring for Jane that telling her the truth makes her distress worse; whereas saying her children will not be out of school for an hour eased her distress.

What does the virtuous care provider do when faced with such a truth-telling dilemma? Tuckett (1998; 2012) states that the deficit of conduct-based theories, such as deontology and consequentialism, is that they present potentially conflicting solutions in such dilemmas without offering any guidance on how to apply them. Tuckett then argues that virtue ethics can complete the picture by the care provider being guided by the virtues in the application of seemingly abstract principles. Tuckett suggests that someone acting from a compassionate motivation will be able to do the right thing.

Drawing on the vulnerability discussion above, being faced with a human being who is more-than-ordinarily vulnerable to being harmed from the truth, a virtuous care provider would feel compassion and be moved by this feeling to act in a way that is sensitive to this.
The decision is still finely balanced as a compassionate care provider might decide to tell the truth in a compassionate way. Honesty is a virtue that many would see as an essential character trait for a care provider. Now, if a white lie is told, someone may challenge the care provider by saying that they could not possibly have been motivated by a *virtue of honesty* in their response to the woman.

Furthermore, honesty is closely linked to trustworthiness, arguably another key virtue when responding to vulnerability (Sellman 2011; McKie and Swinton 2000). It seems open to question if a care provider who tells lies is someone in whom people would wish to place their trust, and as such, whether they could be considered to be virtuous. There is room for some argument here. There may be times when some forms of deception should be tolerated. This may be such an example where that is necessary to lie in order to avoid repeated distress in a situation where the truth cannot be accepted.

### 5.4.3 PRACTICAL WISDOM AND THE DOCTRINE OF THE MEAN

One way to try and make such decisions is to employ Aristotle's *doctrine of the mean*, which states that a particular disposition should be neither overly employed nor underdeveloped in one's character (Aristotle 2009 [1106a14-1109b26]; Banks and Gallagher 2009). Absolute honesty in all situations can lead to the vice of tactlessness, which is to be avoided in a similar way to absolute dishonesty (Kraut 2012). Other examples include politeness, which leads to the vice of obsequiousness when in excess or rudeness when in dearth; alternatively, courage, which leads to rashness in excess or cowardice when deficient.

It is important to highlight that for Aristotle, to aim for the mean does not imply that there is a correct amount of a particular disposition to aim for *per se*; it is relative to the individual and the circumstances in which they find themselves (Hughes 2001b; Aristotle 2009 [1107a1-7]). Aristotle also argues that not every disposition admits to a mean, giving the examples of spite, envy and shamelessness as emotional responses that are bad by definition (Hughes 2001b; Aristotle 2009 [1107a8-27]). Aristotle (2009:31 [1107a10]) adds to these, examples of particular actions that ‘imply badness’ such as adultery, theft and murder. Conversely, it seems possible that full trustworthiness (as opposed to being considered trustworthy by particular individuals) may simply be *good* by definition and not admit to a mean after all.
The doctrine of the mean, despite being an intuitively appealing concept, is not immune from criticism. Kant (1996d/1798: 532) sees as contradictory the idea that virtue can occur from the result of a mean between two vices.

‘The distinction between virtue and vice can never be sought in the degree to which one follows certain maxims; it must rather be sought only in the specific quality of the maxims (their relation to the [moral] law).’ [original emphasis]

In contemporary times, Kraut (2012) agrees that the application of a quantitative measure to the nuanced area of ethical decision is insufficient to express the complexities involved; suggesting that the idea of aiming at the mean in practice merely becomes another way of saying “making the right decision”. However, it seems fair to say that the idea does broadly reflects a truth and seemingly points to something greater that underlies it. As Ross (1995:203-4) states:

‘The Greeks were right in holding that to produce anything good of its kind – a healthy body, a beautiful work of art, a virtuous action – certain quantitative relations are required; quality rests on quantity. As applied to virtue the doctrine is not, perhaps, very illuminating, but there is an element in it which is true.’

Linked to this is the notion of practical wisdom (or phronesis) on which Aristotle argued that virtuous decisions depend. The doctrine of the mean is not the source of good character or a decision procedure; it is merely a way of describing the virtues that would be endorsed by someone with practical wisdom (Kraut 2012; Hughes 2001b).

Practical wisdom, when developed as an intellectual virtue, arguably enables good decisions to be made and good actions to be taken. In simple terms, practical wisdom is a life skill that has to be developed; yet practical wisdom still requires a virtuous end or goal to aim at. As Aristotle states:

‘Virtue makes the goal right, practical wisdom the things leading to it’

(Aristotle 2009 [1144a7-8])

This quote suggests that the goal needs to be set before wisdom can be employed to determine the means to get to it. Such an interpretation, then begs the question of how the goal is set in the first place. In response it turns out that practical wisdom and what Aristotle refers to as ‘moral’ virtue actually work together in his vision (Hughes 2001b; Ross 1995). If moral virtue is absent, and therefore the goal is not good, then the skills
needed to carry this out are not from practical wisdom but merely cleverness. On the other hand, moral virtues without practical wisdom remain undeveloped, useless or even harmful.

Returning to the concern that motivated discussion of the doctrine of the mean; it was that moral virtues such as compassion and trustworthiness may conflict. From an Aristotelian position of the *unity of the virtues*, it can be presumed that the virtuous care provider would have a disposition towards both compassion *and* trustworthiness. It is a matter of knowing when to be trustworthy and perhaps more frank or when to be compassionate which might incline someone to be more tactful. As Hughes (2001b:109) points out

> The moral virtues, being states of appropriate emotional balance, respond to features of the situations in which we find ourselves. In so doing, they alert us to the existence of those features and so offer us starting points for choices. Our choices are motivated by our virtuous inclinations, indeed; but what is of central importance is that they express our refined understanding of what to do and why.'

Practical wisdom works with virtuous inclinations and shows how they can bring about good action. However, the expectation that care providers should aim to recognise the virtues of compassion, courage, trustworthiness, patience, commitment, and so on in themselves and others; further cultivate them and then use these judiciously may be overly ambitious. Also, it could suggest that *only* those people who develop these attributes sufficiently in their character are suited to making and carrying out ethical decisions for dementia care. It seems to imply an *elitist view* and taken to an extreme this would suggest that an ethical model based on this idea is a redundant instrument in the hands of someone without the necessary attributes.

So the intention is to argue against this elitist interpretation. There is a reasonable case to suppose that a wide range of people can develop their virtues through moral education.

5.4.4  MORAL EDUCATION

Sellman (2009) suggests that the way that moral education takes place in a virtue ethics context is dissimilar from the model of teaching and learning in higher education.
institutions. This is primarily because for virtue ethics the aim is to improve the moral character of the students, and the best way to do this is by the *emulation* of others who are understood to have high levels of virtue. This arguably differs from the teaching method for subjects such as mathematics or history that are assumed to be taught not by emulation of practice but by providing the students with theoretical knowledge.

Some support for the idea of the primacy of practical learning as an important part of moral education can be found in the concept of *praxis* (McKie and Swinton 2000). Praxis, understood as knowledge-in-action acts as a way that the moral community as a whole can gain knowledge by reflecting on their practice in moral terms. This knowledge is then passed on through mentorship. However, McKie & Swinton do state that praxis is not a substitute for *theoria* or theoretical knowledge but complimentary to it, suggesting there may be more of a role for theoretical learning than in Sellman (2009). Nonetheless, there is a significant line of reasoning that sites the moral education of care providers in the realm of practice. As such, the presence of *practice mentors* gains importance as these are the people on whom modelling should take place.

It may not be as clear-cut as this, however. Firstly, pressure can be put on the idea that a moral education is somehow different to education in other subjects. In the constructivist model of education, the important thing is what the student *does* to construct knowledge; knowledge is not understood to ever be transmitted by instruction (Biggs 2003). In other words, learning is always an active process and it is going to be a process involving knowledge-in-action whatever the subject. This can be extended to the idea of emulation. When learning a seemingly theoretical topic such as mathematics, it is still possible to emulate a mathematics teacher by observing how he or she approaches new problems in a similar way that a virtuous care provider dealing with problems in practice can be emulated.

So, moral education may not be a distinct case. It could be possible to learn from exemplars in a number of disciplines. Nonetheless, there is a fair consensus for the idea that moral education in the caring professions should focus on practical examples in order for it to be relevant to people (Woods 2005; Holland 1999). It seems reasonable that a mentor or teacher could be emulated either by the way that they respond to the dilemma in the classroom or in *real time*. Responding in a real practice situation is likely
to be messier due to the reality of practice, though as an example it also benefits from that reality by showing what can actually be done by the exemplar themselves. However, due to its messiness, the response may be a less than perfect example for emulation from the exemplar's point view. So having time to reflect on the response and return to it outside of practice would also be an advantage.

Another source of wisdom for people wishing to develop their caring practice is to engage with literature on the topic. Banks and Gallagher (2009) propose that this can enable the development of care provider's moral imagination in response to the needs of those in their care. A related point here is that sources of wisdom for care providers can be drawn from their broader experience. Care providers vary in the life experience they have to draw on. This broad life experience is relevant to the sorts of ethical decisions that are made (Toiviainen 2005). After all, the experiences and people from which we learn and develop our character are varied and reflect our life as whole. As Sellman (2011: 191) rather aptly puts it:

‘...our teachers are all around us and we learn from them in subtle, unplanned, and unexpected ways....’

When making this comment, Sellman is referring to fact that nurses can be educated in informal as well as formal ways. It is not just during a professional education programme that character development can occur. This is in tune with the notion, argued for above, that the boundary between personal and professional is porous. The nurse's character outside of work is a relevant notion. For other groups of care providers, such as family carers, the boundary between personal and professional is minimal or non-existent in their caring practice.

So the idea that we have teachers all around us is a particularly relevant one here when put together with the idea that care providers form a diverse group that includes professionals and non-professionals. It is worth reiterating that there is nothing here that challenges the idea that professionals are care providers who have a number of assured character attributes and academic attainment required in order to be admitted to a profession. It is merely stating that moral education is something that is open to everyone.
As character development is something that is open to professional and non-professional care providers alike, it is hoped that through the development of character, ethical care can be provided. Exemplars provide an important part of this moral education, and these can be found in everyday life as well as through literature or more formal learning. Furthermore, having a broad base of learners and exemplars helps dissolve the criticism of virtue ethics as being based around an elite who aim to indoctrinate those who they see as worthy of receiving such education.

5.4.5 PROBLEMS WITH THE FLOURISHING ACCOUNT IN THE CONTEXT OF DEMENTIA CARE

At this point it is worth casting a more critical eye over the extract from MacIntyre (1999: 5) quoted earlier in the chapter:

‘...the virtues that we need, if we are to develop from our initial animal condition into that of independent rational agents, and the virtues that we need, if we are to confront and respond to vulnerability and disability both in ourselves and in others, belong to one and the same set of virtues, the distinctive virtues of dependent, rational animals, whose dependence, rationality and animality have to be understood in relationship to each other.”

Sellman (2011) suggests that there is a problem with MacIntyre’s account here as it links human flourishing with the ability for independent practical reasoning. It therefore suggests that people without sufficient mental capacity to reason practically cannot fully flourish as human beings. This further quote from MacIntyre (1999: 97) illustrates this point:

‘We have so far then identified two crucial respects in which the virtues are indispensable to human flourishing: without developing some range of intellectual and moral virtues we cannot first achieve and then continue in the exercise of practical reasoning; and without having developed some range of those same virtues we cannot adequately care for and educate others so that they first achieve and are then sustained in the exercise of practical reasoning.’

This problem arises for Sellman as he argues that the work of care providers (specifically nurses) is to promote human flourishing of those in their care. MacIntyre’s account appears to suggest that such flourishing is not possible for patients with reduced mental capacity, so nurses are left unable to achieve this for them.
Sellman does recognise that, as human beings, nurses do flourish too through the pursuit of nursing:

‘Thus, in pursuit of nursing as a practice not only is the flourishing of patients but also the flourishing of nurses qua humans is enabled.’

(Sellman 2011: 104) [original emphasis]

Yet, this opens up a question. In terms of an ethical model, is the important thing to develop virtues that aim for human flourishing by care providers, care recipients or both? It seems open to debate how much the virtues of the nurse or other care providers can be dependent on their ability to promote flourishing of the people in their care. Such a line of argument appears to suggest that those who care for people who are unable to fully flourish are themselves going to struggle to fully flourish as care providers. Yet, this appears to go against the otherwise appealing idea that virtues such as courage, patience, trustworthiness, open-mindedness and so on are arguably more necessary when caring for those who are most challenged in terms of their flourishing. It seems to follow that caring for people with such challenges provides a greater opportunity to cultivate these virtues in the care provider.

Secondly, what virtues might be best developed in people receiving care in order for them to flourish? Banks and Gallagher (2009: 44-5) state that there are moral, social, intellectual, emotional and physical virtues to be developed by health and social welfare in order for flourishing to be promoted in each of these domains. Some of these fit better than others as virtues to be developed by people with dementia who are receiving care.

Sellman (2011) aims to keep the human flourishing account for care recipients by arguing that nurses should help people in their care to flourish to whatever extent the capacities of those people allow. This appears to solve the problem with MacIntyre’s approach by denying the need to categorise recipients of care into those that have different degrees of practical reasoning skills.

However, there is a case for solving the problem in a different way by not directly linking the flourishing of the care provider with the flourishing of the individual care recipient in ways that are unattainable. After all, as mentioned above, part of the attractiveness of the virtue ethics approach is that it is not dependent on the capacities
of the care recipient. It is suggested here that the care recipient having reduced capabilities can actually help cultivate virtues in the care provider and it is on this that good care depends. With this proposed approach, there is no need to reject the general idea that part of having a good character can involve aiming at the flourishing of others in certain ways. It is merely to clarify that it is virtuous intentions and their associated actions originating in the character of the care provider that should be the primary basis for virtue ethics, rather than the actual flourishing of the care recipient based on human excellences that may no longer be possible.

This position is more in line with the virtue ethics associated with Slote (2001). It is proposed here that Slote’s agent-based virtue ethics is preferable for the endeavour of ethical dementia care as it is based fundamentally on character of the care provider and not on the notion of human excellences.

5.5 ADVANCING THE VIRTUE OF RECEP TIVITY

In his early work, Slote (2001:7) states that an action is only good if it is done by someone of virtuous character as the ethical status of actions is entirely derived from claims ‘...about the motives, dispositions, or inner life of moral individuals.’ Therefore, following a course of action because it is recognised as being virtuous by its outcome, is too much of a departure from the agent as the sole source of the virtuous action.

Slote’s view of agent-based ethics puts pressure on the notion of practical wisdom (Russell 2008). This is because Slote (2001) suggests that the virtuous individual, if in possession of all of the relevant facts, will have no need to deliberate about the course of action; he/she will be able to act virtuously in caring merely due to having the necessary moral virtue.

‘...she [an ideal caring person] can act from concern for others without considering whether she is acting rightly or wrongly or, for that matter, caringly or uncaringly...’ (Slote 2001: 193)

Slote’s earlier view which holds a virtue of benevolent caring as sufficient to be an ideal moral individual has since been developed. In later work, Slote (2013) does not state that it is possible to act perfectly as an agent on this basis. As discussed above, many virtues, though appearing to be compelling, can conflict with other similarly compelling
virtues in some situations. For example, to act virtuously in one regard such as with tact leaves one open to criticism to not acting virtuously in another regard such as frankness.

It was *this very conflict* that suggested the need for the intellectual virtue of practical wisdom (phronesis) in order to deliberate about the wise choice when in a difficult situation. Yet, Slote (2013) rejects this Aristotelian idea that wisdom will be able to generate the right choice in such situations, Instead, he states that such conflict demonstrates the *impossibility* of moral perfection. This is in tune with an Eastern philosophical approach such as the Zen aesthetic attitude of Wabi Sabi which values imperfection (Cooper 2013, Saito *et al* 1998).

It is from the acceptance of imperfection that Slote instead proposes *receptivity* as the central (but not absolute) virtue. Receptivity involves being empathic to the thoughts and feelings of other human beings. Furthermore, this empathy should not merely be projective, which involves ‘getting in the heads of others’ (Slote 2015: 5). Instead receptive empathy involves:

‘actually identifying with the other person, actually seeing things, however briefly, from their point of view.’ (Slote 2015:5)

Slote argues that if we value receptivity then we will be able to accept our limitations as human beings rather than seeking perfection. For Slote there is a shared tendency in both Aristotelian virtue ethics and modern Western Philosophy to seek perfection through its emphasis on pursuing a rational life plan. Slote makes the insightful point that the things we appear to value most in life, such as friendship are in reality unlikely to result from the use of critical analysis or rational life planning, rather they require receptivity (Slote 2015).

As such, receptivity can be also understood as part of Slote’s overall project of rethinking Enlightenment values. Slote argues that receptivity moves us beyond a reliance on rationality to value also the non-rationality in human life:

‘...receptivity to other people’s opinions and points of view grounds epistemic open-mindedness, fair-mindedness, and rationality in a way that Enlightenment-type thinking has never recognized. But we have also seen [in previous argument] that receptivity of an epistemically nonrational and at least partly
irrational kind is essential to valuable relationships and feelings toward others. We can and should be epistemically rational in most of our thinking about and dealings with the world and the people we come in contact with, but unless we are also receptive toward other people and their attitudes and opinions, we are going to miss out on much of what is most valuable in life. 

(Slote 2013: 214) [original emphasis]

So, a combination of rationality and empathy are necessary for us to have a full appreciation of the good life.

There are a number of possible advantages for dementia care of focussing on receptivity as the central virtue. Firstly, there is a move away from the idea of human excellence being primarily grounded in the intellectual function of phronesis, an ideal that seemingly excludes people with advancing dementia.

Secondly, there seems to be some protection from the criticism (raised above) of moral education being merely indoctrination, as the process of being indoctrinated suggests more of an intellectual than an emotional or empathic process.

Finally, the agent-based approach ensures that the character of the individual who is providing the care is the key factor. This means that the starting point for ethical care, including ethical dementia care, is developing a good character in the care provider, rather than establishing the moral status of the care recipient. However, this does not result in the individual with dementia becoming irrelevant. Indeed, having receptivity as the central virtue means having a full and genuine empathic concern for others by being open to their feelings and preferences.

Despite taking this non-Aristotelian turn, Slote’s proposal need not conflict with the discussion of moral education above. There is a similar need for exemplars of receptivity as there is for the more intellectualised notion of practical wisdom. Again, receptivity can be learned from people both formally or informally, from a range of teachers in planned or unplanned ways.

As such, exemplars of receptivity will not be aiming for perfection, even in receptivity itself, as they know that is an unobtainable aim. However, they have a key role to play as they will be particularly receptive and hence their approval or disapproval towards actions or attitudes of others will act as a sound guide.
5.6 CONCLUSION

The virtue ethics approach described in this chapter aims primarily to develop the personal excellences of providers of dementia care. It has been suggested that an advantage of focusing on the character of care providers is that it avoids difficulties that haunt other ethical views linking the presence of certain psychological attributes in the care recipient to their moral status. Here an argument has been constructed that proposes that the vulnerability of the care recipient, which may be due in part to a lack of these attributes, is an opportunity to develop good moral character in care providers.

Though this idea is clearly applicable to the practice of nursing, it has been argued here that it is equally applicable to the broader notion of caring when understood as a practice in the same manner. The question of “which virtues?” for dementia care has suggested that prominent candidates are trustworthiness, compassion, receptivity, along with the courage to carry them out. However, it was found that these and other prominent virtues can conflict, leading to uncertainty about the correct course of action. The doctrine of the mean, though a useful illustration of virtue, was found to be ultimately unsatisfactory in attempting to resolve such disputes.

Instead, an initial solution was sought in the development of practical wisdom (phronesis) in care providers. This seemingly lofty aim was seemingly made more achievable by basing it in the real life practical experience of dementia care providers. Learning takes place through action, and the role of practice mentors or other exemplars is also crucial. People acting alone in the provision of care for people with dementia may not have access to practice mentors in the same way as in a professional nursing environment; however, a broad range of influences both past, present and literary can be drawn on. Exemplars are all around us.

Yet problems remained. Firstly, how do we select the correct exemplars in life or literature to emulate? One possibility is that the exemplars should be seen to aim at the flourishing of human individuals. If their actions do not help people to flourish, then their character is not worth emulating. Yet, on analysis it was found that this solution meets some difficulties if the flourishing of people with advancing dementia is seen as the measure of the virtue of a care provider. This is because people with advancing...
dementia are increasingly limited in how they flourish in terms of the usual human excellences.

The agent-based view of virtue ethics associated with Michael Slote seems to offer a solution. Here it is solely the care provider’s motives and character that are of concern not human flourishing. In later work Slote has advanced the idea that moral perfection is an impossibility. As such he argues against Aristotlian virtue ethics which hopes to achieve this through the route of practical wisdom.

Instead, Slote proposes receptivity as a virtue of central but not absolute importance. This virtue aims to developing empathy in order to identify with the experience of others rather than the more intellectual notion of practical wisdom. It has been argued here that care providers can cultivate receptivity in the same way as suggested for developing practical wisdom above. There is a similar need for exemplars. It is proposed these can be found in all walks of life; providing learning formally and informally.

It is suggested that this interpretation of virtue ethics is the most useful as it seems to be more in tune with dementia care than Aristotelian forms that focus on flourishing and the intellectual prowess of human beings. The notion of receptivity and the sentimentalist approach to ethics found in Slote’s work is by his own description aligned to the ethics of care (2013; 2007).
6 THE ETHICS OF CARE, EMOTION AND THE ROLE OF
SOCIOPOLITICAL JUSTICE

6.1 INTRODUCTION

The previous chapter discussed virtue ethics as a response to vulnerability. It was suggested that it is an advantage for dementia care to focus on the character of care providers. This was part of a move away from considering the moral status of the individual receiving care as the primary basis of a model for dementia care. The advantage gained by this shift was that by focussing on care providers, it avoids debates about the erosion of moral status of the individual with dementia that may occur due to the loss of autonomy, personhood or other capacities. Furthermore, it has been argued that changes to capacity, rather than being seen as problematic in terms of a lesser moral status, may actually be a potential resource for an ethical response.

As the discussion in Chapter 5 developed, the agent-based virtue ethics of Michael Slote emerged as a promising candidate for dementia care. Slote’s view can be seen as part of a movement that seeks to form a bridge between virtue ethics and the ethics of care. Slote, himself, does not apply his work to dementia care. However, it seems in tune with the needs of people with dementia due to its focus on the caring disposition of the care provider and its recognition of the importance emotion and empathy play in our moral lives (Slote 2013; 2007).

This chapter will initially explore the emergence of the ethics of care in an historical context. Here links between the ethics of care, virtue ethics and 19th century sentimentalism can be seen. However, there are a number of distinctions too. This pressure is particularly felt in the way that the traditions put different emphases on obligation, relationships and justice. It will be examined how the ethics of care views these notions and how this might affect dementia care ethics.

From this, the beginnings of an ethical model can be outlined based on the ethics of care perspective. This will then lead to a critical evaluation of the ethics of care, and an argument that the virtue of receptivity has a role in responding to these criticisms.
6.2 THE ETHICS OF CARE AND VIRTUE ETHICS COMPARED

6.2.1 THE COMMON FOUNDATION OF MORAL SENTIMENTALISM

It may be assumed that, virtue ethics has its roots in the ancient world; the ethics of care in the modern. However, conceptual links between the two schools of thought can be found. This section will briefly outline the emergence of the ethics of care in both an historical and political context. From this, similarities and distinctions with virtue ethics will be discussed and their possible role within an ethical model for dementia care will be evaluated.

In Western Philosophy, virtue ethics is seen to originate in the classical world view of Plato and Aristotle. However, these ideas were challenged during the Enlightenment, as virtues were sought to be encompassed under the increasingly dominant views of the era such as rights, reason and the promotion of utility (Hursthouse 2013; Slote 2013; Banks & Gallagher 2009). At this time, the philosopher David Hume provided a sceptical voice against the dominance of reason in the Enlightenment and argued for an empirically-driven virtue ethics guided by feelings and sentiment (Denis 2012; Hume 1998/1751).

In dementia care, attention to the emotional aspect of human life is promoted as part of the 'new culture' of care (Kitwood 1997: 135), particularly so in the work of David Sheard (2013). The sentimentalist position of Hume resonates with this. Though Hume’s ethical theory was not care-focussed, his placing feelings (or passions) at the core of ethics would later be shared as a central tenet of the ethics of care (Noddings 1984; Held 2005). As such, Slote argues that the ethics of care is the ‘present incarnation’ (Slote 2007: 4) of moral sentimentalism. Though, Slote also makes a distinction between his care-based virtue ethics and the virtue ethics of Hume. Hume sees moral worthiness as something that can be judged by how much it pleases or displeases people (Garrett 2015; Hume 1998/1751). Slote (2013) shares Hume’s view to some extent but argues against the idea that morality has no more value than anything else that might please or displease us, arguing this move resembles the (amoral) tendency in utilitarian thought.

On the other hand, Garrett (2015) makes the argument that Hume was not a consequentialist due to his focus on virtue and reliance on a moral sense rather than a
calculation of utility being the ultimate arbiter. Nonetheless, the utilitarian consequentialism of Jeremy Bentham does get from Hume the idea that utility can be the measure of virtue. Bentham used this to develop his own position that the amount of happiness resulting from consequences should be the measure of its ethical value (Garrett 2015; Driver 2009).

Ultimately, this idea eclipsed any resurgence of a Humean *virtue* ethics in the eighteenth century. Instead, consequentialism, along with deontology, was to dominate the ethical landscape of Western Philosophy until some years later in the mid twentieth century when a rising dissatisfaction with the two theories (Anscombe 1958) led to a renewed interest in virtue ethics once again (Banks & Gallagher 2009; Hursthouse 2013). Slote’s view, which is based in care and receptivity, forms part of this modern revival for virtue ethics as well as being part of the movement of the ethics of care.

### 6.2.2 THE CENTRAL TENETS OF THE ETHICS OF CARE

The ethics of care is commonly traced back to the psychological work of Gilligan (1982) who claimed that when discussing ethical matters women tend to speak in a different voice (Beauchamp 2005). Gilligan argued that these voices, which stress care, emotions and relationships, are eclipsed by the voices expounding justice and rights that tend to be male.

Gilligan’s findings have been adopted and interpreted by the feminist movement. However, Tronto (1993) is sceptical of how helpful this distinction is for feminism and the promotion of an ethics of care. For Tronto, boundaries between women’s and men’s ethics are drawn as a way that contains women and care rather than promoting it. Tronto concurs with the historical perspective outlined above that sentimentalism effectively ended up on the ‘losing’ side of the debate in the eighteen century (Tronto 1993: 36). Tronto contextualises this as part of a changing world at this time where work was developed more outside of the home. Women started also to develop more public roles but men wishing to maintain control, sought to confine women to the domestic sphere. Tronto (1993) goes on to argue that in order to justify this confinement, the idea was developed that the ethics of sentiments were best suited to women and their place in this private or domestic domain. This move lead to women being identified as sentimental in their ethical approach; whereas men, whose work was
associated with public life, were expected to exercise the more esteemed form of ethical thinking based in reason.

So, for Tronto (1993: 56), the association of sentimentalism and later the ethics of care to women is part of an ‘historical process’ that is political not biological in origin. Rather than separating women’s and men’s voices, Tronto’s vision is to argue for care in a way that does not need such a boundary. For Tronto, an ethic of care should bring care to the forefront of ethical thinking; not as a reaction to oppression from the side-lines but as a central concern for all humanity.

‘Care is not a parochial concern of women, a type of secondary moral question, or the work of the least well off in society. Care is a central concern of human life.’ (Tronto 1993: 180)

The development from Gilligan’s initial findings to Tronto’s more overtly political perspective reflects the evolution of the ethics of care tradition. Since Tronto’s (1993) work, further evolution has occurred resulting in it being now even more widely interpreted (Klaver et al 2014). In order to begin an assessment of the usefulness of the ethics of care for dementia care, the features that are (on the whole) shared by the contemporary tradition will need to be examined.

Firstly, distilled from Gilligan’s original (1982) work, Edwards (2009: 151-153) has formulated ‘five claims’ of ‘care-based’ ethics:

- **Uniqueness claim**: each ethical situation must be treated as unique
- **Caring claim**: our involvement in relationships with others is characterised by care.
- **Emotions claim**: emotions form ‘central aspects of the moral life’ and are ‘guides to action’
- **Privileged view claim**: people who are involved are best placed to know how to respond.
- **Justice claim**: specific to Gilligan’s (1982) view that the ethics of care works on an emotional basis that is not compatible with justice-based approaches.

The ethics of care theorist, Virginia Held (2005: 10-13) argues that ethics of care has the following features:
- It is primarily about the ‘moral of claims of particular others’
- It values emotions such as sympathy, empathy and responsiveness rather than rejecting them.
- It avoids abstract reasoning and universal rules.
- It ‘...reconceptualizes traditional notions about the public and the private’ in tune with feminist thought.
- It has a relational and interdependent conception of persons.

Finally, Klaver et al (2014: 758-9) suggest the following four features for an ethics of care:

- It is based ‘first and foremost’ on relationships and has a relational view of society.
- ‘It is ‘context-bound and situation-specific’ and as such needs to avoid being abstract.
- It is a political ethics that challenges the public/private distinction and has a scope beyond personal relationships.
- It is empirically grounded/informed.

These summaries suggest some contrast in perspective. Firstly, Held (2005) and Edwards (2009) focus more overtly on the importance of the emotions, whereas Klaver et al (2014) emphasise the importance of empirical content of the ethics of care. This seems to suggest a different approach. Though, if a Humean view is taken then the notion of emotions informing good care would be part of an empirical grounding for ethics (Hume 1998/1751). Indeed, describing the epistemological process behind the ethics of care Klaver et al (2014: 759) state

‘It is not just about rational approaches and decontextualized abstract knowledge; rather emotions and tacit knowing are also valued as important epistemological sources, which therefore have to be critically cultivated.’

Edwards highlights a potential tension between the role of emotion in ethics of care and the more rational basis for justice. However, this concern is more specific to early views such as Gilligan’s (1982) on which Edwards’ five claims of care ethics are based. Later views such as Held (2005) and Tronto (1993) aim to reconcile this tension, seeing
justice and care as being compatible if the assumption of their polarised origins is
removed.

Another contrast is that Klaver et al (2014), Held (2005) and Edwards (2009) interpret the issue of a public/private distinction slightly differently. For Held, this is about the ethics of care as a feminist vehicle for social justice within the so-called private relationships that law and ethics have arguably ignored. Klaver et al (2014:759) emphasise developing just institutions and having a scope ‘...broader than personal relationships’. Yet, to move the scope beyond personal relationships is in tension with their first feature, seemingly making Held’s view more consistent here. Edwards (2009:166) argues that the ‘public-domestic dichotomy’ is actually somewhat dissolved by caring (and nursing in particular) as it involves acts that can be seen to straddle both the public and domestic domain. For Tronto (1993), as discussed, the public and private domain is a political construction that needs to be dissolved in order for care to develop.

Despite these differences in some aspects, the accounts of Held (2005), Klaver et al (2014) and Edwards (2009) broadly concur. They each emphasise the importance of relationships for an ethics of care. They also agree on the importance of context, direct involvement and the need to avoid abstract reasoning. Held and Klaver et al, along with Tronto (1993) emphasise the political nature of the ethics of care as well as how it challenges the notion of the public/private distinction.

These shared features appear relevant to informing an ethical approach for dementia care. Having caring relationships at the centre of ethics, along with the idea of interdependence has been demonstrated as an important theme in previous chapters. Also, it seems fair to state that dementia care is a practical endeavour and an ethical model that focuses on the tangible elements of real situations may well be more useful than one that focuses on generalising and abstract reasoning.

Finally, the prominent role of emotions is also promising in light of the assertion that dementia care works primarily on an emotional level (Sheard 2013). For Sheard (2008) ‘feelings matter most’ and person-centred is more about ‘being’ than doing.

Sheard’s approach is in tune with the theme of emotion-centred care and some aspects of Hughes and Kitwood work discussed in previous chapters. However, his work does not seek philosophical grounding, nor has it been developed into an ethical model. As
such it does not seek to answer the key philosophical questions nor has it been applied to ethically challenging situations.

The ethics of care can state a strong claim for consideration in dementia care; though it remains unclear where this leaves virtue ethics, as neither virtue nor virtue ethics feature explicitly in the descriptions of an ethics of care above. It is important at this point, therefore, to clarify the degree and nature of the collaboration between the two approaches, and its relevance for dementia care in particular.

6.2.3 SIMILARITIES AND DISTINCTIONS BETWEEN VIRTUE ETHICS AND THE ETHICS OF CARE

The conclusion of the previous chapter highlighted as promising the idea of a bridge between virtue ethics and an ethics of care. The most prominent candidate for this can be found in Michael Slote’s work culminating with his account of virtue ethics based on receptivity (Slote 2013). Recall from Chapter 5 (5.5), that a key element of receptivity is that it involves valuing non-rational elements as essential in our relationships to other people, allowing us to be open to others’ opinions and needs. Slote expands on this theme below:

‘If moral judgments and claims depend on our capacity for approval and disapproval, then they depend on our capacity for empathically taking in the warmth that we see others expressing in their actions or attitudes and the lack of warmth or coldness that those who are indifferent or malicious toward third parties exhibit in their actions or attitudes. And to be warmed or chilled by another’s warmth or coldness is not to do something deliberately, but to be to a high degree emotionally receptive to what is going on around us. So on the view just described, receptivity lies at the heart of moral judgment and moral belief and is therefore essential to a very important part of our life and thought.’ (Slote 2013: 200)

It is important to note the Humean idea (Hume 1998/1751) that receptive individuals can feel ‘warmth or coldness’ when exposed to the actions of others. These actions produce this warmth depending on the amount of receptivity that the agent employs.

The notion of being receptive and developing a virtue of receptivity is in tune with the more widely understood features of an ethics of care. Though there is much of the ethics of care which is shared with virtue ethics more generally. Virtue ethics as a whole also seeks to avoid abstract reasoning and rules, has a central place for emotions and is
context and situation specific (Hursthouse 2013; Banks and Gallagher 2009). This is probably why some commentators, including Beauchamp and Childress (2013: 35) interpret care ethics as a form of virtue ethics. The similarities are also recognised by Held (2005: 19)

‘Certainly there are some similarities between the ethics of care and virtue theory. Both examine practices and the moral values they embody. Both see more hope for moral development in reforming practices than in reasoning from abstract rules. Both understand that the practices of morality must be cultivated, nurtured, shaped.’

However, there are also some key points of departure. For Noddings (1984), virtue in caring is build up in the context of caring relationships and it is not the same as having virtues as abstract ideals. As she rather frankly puts it:

‘We must not reify virtues and turn our caring toward them.’ (Noddings 1984: 96)

Sander-Staudt (2006) aims to outline some of the distinct qualities of virtue ethics and the ethics of care, for which she employs the alternative term, care ethics. Firstly, the apparently self-evident point is made that the concept of care is central to care ethics in a way that it is not in virtue ethics and similarly virtue does not have the same prominence in care ethics as in virtue ethics. Sander-Staudt (2006: 35) goes on to state

‘This is not to say that CE [care ethics] is not interested in achieving virtuous care or thinking about care as a virtue. But CE scrutinizes virtue in the context of how best to achieve the goals of care, while VE [virtue ethics] scrutinizes care in the context of how best to achieve virtue and a flourishing life.’

Sander-Straut (2006:35) then makes the following argument to highlight the role of a virtue of care in virtue ethics

‘Although Aristotle claimed that virtues must be practiced and not just possessed, there is no guarantee that every application of caring virtue will be tied to a certain dimension of caring practice. According to Aristotle, individual virtue is in part determined by social positioning. Given this, privileged men (and women) are judged to exhibit the virtue of care without being responsible for the more thankless aspects of caring practice..... Even if care is defined as the most central of virtues, and one that must be practiced on all levels to be fully met, the competing focus on other virtues and virtue ethical concepts means that VE is
likely to take longer than CE to highlight the imperative and injustice of caring practices.’

The above suggests that care ethics gives a more prominent place to the role of justice in supporting care than virtue ethics. Justice has a central role in virtue ethics also, but care ethics is more equipped to highlight issues of sociopolitical justice in *practical everyday caring* for both paid and family care providers.

A sociopolitical justice focus would have to attend to the inequalities of how care is organised. Families providing care for people with dementia may find that there is a considerable physical and psychological demand placed on them (Aggarwal *et al* 2003). Gibbons *et al* (2014) found that women experience significantly more burden than men when caring for a spouse with dementia. Ward-Griffin *et al* (2006) report similar expectations falling to daughters to care for their mothers with dementia. This resonates with Tronto’s (1993) argument outlined above that it is a *political process* that brought women to be seen as caring and is linked to them being confined to the domestic environment.

In some cases, the demands of caring work may be transferred outside of the family, particularly if the family is in a privileged position. Barnes (2012) observes that paid care work in wealthier countries carried out in people’s own homes is predominately done by migrant workers who she argues are more at risk of being exploited due to their marginalised status. Tronto is more robust here pointing out that care is gendered, raced and classed. As Tronto (1993: 113) rather bluntly puts it:

‘Care has mainly been the work of slaves, servants, and women in Western history.’

These accounts suggest that the demands of caring fall unfairly on certain members of society, which may affect the caring relationship and the ethical quality of the care provided. The underlying argument here is that in order to value care, and help enable good care, it is necessary to value the people who are carrying it out (Kittay 1999). This will be returned to in more depth below. In the meantime, it seems fair to advance that this underlying dialogue in the ethics of care has a central role to play in elevating the status of dementia care *along with those who provide and receive it* in a way that is more politically overt than is found in virtue ethics.
Nonetheless, Sander-Staudt’s (2006) criticism (quoted above) of virtue ethics as more for the privileged does rely on an interpretation of Aristotelian ethics that was rejected in the previous chapter. As such it would be going too far to generalise this to views of virtue ethics that are more care-centred.

Sander-Staudt also raises the concern that care providers may perceive virtue as burdening them with a personal ideal that cannot be lived up to; whereas care ethics does not have this tendency, instead focusing on political and social structures. However, again this argument against virtue ethics was challenged in the previous chapter. There it was argued virtue ethics should focus on education and aspiration, primarily through emulation. Care providers in an array of different social positions can still find exemplars in everyday life on whom to model better practice that is reasonably attainable.

Also, it is not apparent that care ethics is clear of the criticism of putting pressure on care providers. Though it commonly recognises the importance of social justice, some theorists in the ethics of care tradition focus on obligations to care resulting from the moral claims made by particular others (Held 2005; Kittay 1999; Noddings 1984).

Noddings (1984: 84) describes it thus:

‘I am obliged, then, to accept the initial “I must” when it occurs and even to fetch it out of recalcitrant slumber when it fails to awake spontaneously. The source of my obligation is the value I place on the relatedness of caring.’

However, this is not always the case, and others such as Brannelly (2011) and Tronto (1993) argue that obligation has lesser place in the tradition. An ethics of obligation if accepted is one that may give the care provider fewer options than an approach that does not have recourse to this notion.

The quote from Noddings above links to another distinction that can be found in how care ethics and virtue ethics perceive relationships. As Sander-Staudt (2006: 36) suggests:

‘.....CE [care ethics] construes the entire self as constituted, known, and maintained through relationship, and construes virtue as a quality that nurtures relationships appropriately.’
Here links can be seen with this predominately feminist idea of the social constitution of the self (Mackenzie & Stoljar 2000; Christman 2004).

In contrast, virtue ethics draws attention primarily to individuals rather than the relationship (Banks and Gallagher 2009) and this is particularly the case with Slote’s agent-based view. The importance of this distinction is summed up by Held (2005: 19)

‘In my view, although there are similarities between them and although to be caring is no doubt a virtue, the ethics of care is not simply a kind of virtue ethics. Virtue ethics focuses especially on the states of character of individuals, whereas the ethics of care concerns itself especially with caring relations.’

For this reason, Held argues that Slote’s aim to unify the two ethics is problematic. In response Slote draws on the concept of receptivity that he shares with Noddings

‘Noddings has argued that ethics of care should view caring as primarily a relationship and only secondarily a trait or virtue of individuals..... But, receptivity is a trait or characteristic of individuals, so if, as Noddings and I both believe, it is essential to all caring relationships and lies “at the heart of human existence,” care ethicists shouldn’t perhaps think of relationships as ethically more important or foundational than individual character traits.’ (Slote 2013: 221)

Slote’s view seems in line with the idea of a society of interdependent individuals where receptivity is located in the consciousness of individuals rather than in the more nebulous realm of their relationships. However, his conclusion is measured with the phrase ‘shouldn’t perhaps think’ and maybe this suggests some uncertainty. After all, it could be argued that receptivity cannot exist without a relationship and this would make relationships necessary and arguably foundational. However, though Slote appears to be more on the side of virtue ethics in his notion of relationships, in earlier work (Slote 2007) he takes the ethics of care perspective when discussing the role that empathy has in generating obligations.

So there seems to be some tension in trying to combine care ethics and virtue ethics and Slote’s position gets tangled up in this. This tension can be found in the fact that obligation and relationship have a lesser role in virtue ethics and that justice is understood differently. Attention will now turn in more detail to how these concepts are understood in the ethics of care, and its possible implications for dementia care.
6.3 RELATIONSHIPS, OBLIGATION AND SOCIOPOLITICAL JUSTICE IN THE ETHICS OF CARE

6.3.1 THE IMPORTANCE OF SOCIOPOLITICAL CONTEXT IN CARE RELATIONS

Relationships and relational ethics are a recurring theme in this thesis and the concept has been explored from various perspectives. As discussed in Chapter 2 (2.10), relational ethics can be associated with a social conception of the self (Christman 2004). Kitwood (1997) considered how the notion of forming I-Thou relationships (Buber 1959) might create a sound basis for empathic dementia care (4.9.1). Overall the discussion of relationships has developed in a sceptical direction culminating in the tensions outlined as to whether relationships or character should be considered foundational.

A distinction can now be made between the effect that taking a relational view has on recipients of dementia care (explored in previous chapters) and the effect it might have on care providers.

The risk identified for the individual with dementia in seeking a socially constituted view of personhood was that these social forces may actually end up overwhelming any remaining self-determination. The people surrounding the individual may end up imposing a particular perspective due to the power of these social influences (Donchin 2000). Even if these forces are benevolent there is a risk of paternalism and taken to its extreme, these forces can become malign.

Shifting the effect of care ethics and its social view of the self to the care provider reveals a subtly different result. The risk also applies in that the autonomy of the individual care provider might be overwhelmed by giving too much consideration to social perspectives. However, in terms of relational autonomy there is also an opposing risk that people’s decisions may be respected inappropriately as the social conditions have not been considered enough (Donchin 2000). Put simply, the opposing risk is that care providers from oppressed groups are not making an autonomous choice about choosing to care due to this negative social context. This worry is made more forceful by the observation discussed above that a sizable number of people who care are from politically oppressed groups. Oshana expresses the concern in general terms:
‘In order to be autonomous, a person who is in a society must find herself within a set of relations with others that enable her to pursue her goals in a context of social and psychological security.’ (Oshana 1998: 94)

As pointed out by Christman (2004) and Holroyd (2009), this line of thought leads to the seemingly paternalistic treatment of care providers. This is because people in perceived oppressive situations could in fact have their decisions overruled in their best interests as they cannot be autonomous under such social conditions.

The crux of the matter appears to hinge on whether the social forces, to which relational views may have us yield, are positive or negative. If we are part of a positive supportive community then yielding to a relational view seems preferable, though carrying with it the risk of limiting individual choice to some degree. However, if the forces are malign or oppressive then it seems that these social forces can disable our ability to be autonomous in a meaningful sense and therefore need to be tackled.

Interestingly, this argument can also be applied to the care recipient. It seems reasonable to suggest that the malignant social psychology described by Kitwood (1997) may in fact lead to a mindset in the care recipient with dementia that concurs with this malignant psychology. If the dementia is less severe, then decisions made under this mindset may meet the internal psychological criteria for autonomy, as outlined in Chapter 2. However, the very fact that this decision is made in the context of an oppressive social situation will render it not autonomous using the relational external social criteria.

So, caring relationships have a complex make-up. On the one hand they can be enabling and positive for the two parties involved. However, caring relations can also be oppressive either for the recipient, provider or both.

This background raises some important issues for the ethics of care. There is the question of how the ethics of care might respond to the potential for injustice, both for care receivers and those providing the care.

6.3.2 OBLIGATION AND MUTUALITY IN CARING

In the discussion of vulnerability in the previous chapter, it was raised that Kittay (1999:55) sees care providers as having ‘vulnerability-responsive obligations.’ It is
worth noting initially that Kittay has a type of care in mind here where the care recipient is particularly dependent on the care provider to meet their needs. In these situations, Kittay argues that the care recipient is vulnerable to the actions of the care provider in the sense that they are dependent on them for care. This dependency in another human being then obligates the care provider to respond. This is even the case if care providers find themselves in such a relation without choosing it voluntarily. Though some acts resulting from a caring obligation might be delegated to others, the care provider remains ultimately responsible for the caring obligations being carried out.

Recall that Kittay is not alone in using the language of obligation as Noddings (1984) also uses the term frequently in her work and Slote (2007) favours this term in his book *The Ethics of Care and Empathy*. However, some care ethicists prefer to use the term responsibility rather than obligation. It is argued by Barnes (2012) and Tronto (1993) that this language reflects a less rigid structure in terms to how people should respond, and therefore shows more fidelity to the ethics of care approach. Yet on closer scrutiny, this difference of language does little real work. Though it may suggest a different context, it is hard to imagine what a responsibility that does not entail any obligations would be? Furthermore, both obligations and responsibilities can be met in varying ways so a flexibility of response is implied by either term. It seems that though the terms may suggest a different context; they are ultimately interchangeable.

The pertinent point becoming recurrent in this chapter is that the coercive nature of the social structure results in women often finding themselves in the situation of being responsible for dependency work and therefore obligated to respond. As Kittay (1999: 64) acknowledges

`Women, and others who have done dependency work because of coercive conditions or without adequate compensation, have too long simply accepted these unfair allocations as social facts, thereby colluding with an oppressive and exploitative situation.'

So it follows from this that acceptance of these conditions is arguably unjust and a decision to behave in such a way may be challenged as not autonomous from a relational point of view. In order to tackle this, Kittay shifts the focus to moral
obligations that society has to the care provider (as a dependency worker) enabling a more equitable picture to develop.

For Kittay (2009; 1999) the answer lies in putting mutuality at the centre of caring. This starts with the idea that care received from a mother is reciprocated. It is this mutual exchange of care that preserves human society:

‘No one can survive and become part of the human community without the interest of some mothering person(s) who has provided a degree of a preservative love, a concern in fostering the individual’s growth, and a training for social acceptability. When we respect an individual as some mother’s child, we honor the efforts of that mothering person and symbolically of all mothering persons.’ (Kittay 1999:69)

So, part of this vision is to ensure that the carers themselves are also respected in order to be able to care for others. It is this that inspires Kittay to refer to the principle of doulia. Doulia is derived from the contemporary definition of a doula meaning someone who supports a mother to care for a new baby both during and after childbirth. Kittay describes doulia in these terms:

‘Just as we have required care to survive and thrive, so we need to provide conditions that allow others – including those who do the work of caring – to receive the care they need to survive and thrive.’ [italics removed from original] (Kittay 1999: 107)

For Kittay, doulia is therefore ‘a public conception’ (1999: 108) and it results in an obligation on society to support those who care in order to reflect the interdependent reality of our human existence. Kittay has not applied her ideas to dementia care in particular. However, Kittay’s notion of doulia seems to respond to the concerns outlined above regarding the potentially oppressive position of care providers in dementia care. People with dementia and their care providers can make claim to being a mother’s child and therefore need to be treated fairly as part of a society of nested dependencies:

‘The equality concept inherent in the idea that we are all some mother’s child utilizes such a notion of nested dependences. This equality insists that our full functioning presumes our need for and ability to participate in relationships of dependency without sacrificing the needs of dependents or dependency workers.’ (Kittay 1999: 132)
Let’s examine how Kittay’s interpretation of the ethics of care might work in practice by returning once again to the dilemma from Schermer (2007). Recall, that this involved a woman with dementia banging on the door of a locked ward begging to be let out to collect her long since grown-up children from school. It was found by people caring for the woman that telling her the truth makes her distress worse; whereas saying her children will not be out of school for an hour eased her distress.

Putting oneself in the position of being the care provider at the door with this woman, it is not at all clear how such a notion might guide a care provider in the seemingly central question of whether they should tell the truth or not. For Kittay (2009: 624), being a *mother’s child*, grants the woman with dementia personhood and therefore an entitlement to ‘just treatment and protection’. However, the question is begged what personhood would have to be in order to ground such entitlements. In Chapter 3 (3.4.2), the discussion of this example centred on whether the *psychological attributes* of the woman with dementia entitled her to a prima facie right to be told the truth, based in the moral status of personhood from these attributes. However, Kittay is quite clear that psychological attributes are not the relevant thing as far as her conception of moral status is concerned (Kittay 2005).

Instead, Kittay’s notion of being a mother’s child is merely equivalent to saying human being (as all human beings meet this criterion). So, it raises the question why Kittay would use the term a mother’s child and not just say human being. Part of the answer can be found by reflecting on the context in which Kittay writes. Kittay, herself, is the mother of a child with profound disabilities and it is this that has motivated her to pursue this philosophical issue (Kittay 1999; 2005; Kittay 2009). Kittay champions the cause that people with severe cognitive and physical disability have a moral status based on their status as cared-for human beings rather than their psychological capacities. For Kittay the fundamental caring relationship of mother and child is central to who we are and the moral status we hold.

Ultimately, it is the claim to this moral status that obligates people to respond, Kittay believes. Kittay describes this moral status as personhood (Kittay 2005; Kittay 2009). Yet, having the care requirements of a mother’s child is a status to which all human beings are entitled and it follows for Kittay therefore that all human beings have
personhood. If this is accepted, it remains unclear how the reference to a being a mother’s child adds more than merely saying that personhood is a status granted to all human beings. The latter claim was investigated in Chapters 3 and 4 and found to be philosophically wanting.

Arguably, what marks out Kittay’s view as relying on more than humanness is that it puts care at the centre of the claim. It is being cared for that provides the status she describes. However, it is still a status that is based on humanness. Kittay does not seem to be arguing that being worthy of care is separate from humanness, in fact the two are closely intertwined.

Returning to the example, it is reasonable to suggest that Kittay’s view (along with many others) would obligate a caring response in this situation. This might be similar to the discussion of this example in Chapter 5 (5.4.2) which looked to the care provider to respond in a way that reflected a virtue of compassion. It could be advanced, therefore that the compassionate caring response to this human being would be to tell a white lie. However, recall that this response could be challenged by the opposing argument that the care provider should exhibit the virtues of honesty and trustworthiness, or that the truth should be told in a compassionate way. Also, the care provider may believe that a caring response actually involves a responsibility or obligation to be honest in their caring interactions.

There is also the complicating factor that Kittay’s principle of doulia requires that the care provider is also respected. This has not been a factor in earlier discussion of moral status. It may be that the care provider finds the reaction of the woman with dementia, when she is told the truth, particularly distressing. In this case, there is possibly now an additional reason not to tell the truth. On the other hand, it may be that she finds telling white lies distressing, and if this response is obligated then it may mean the care provider is not being supported in a way that might be expected by doulia. Seemingly, there is a balance to had in being supported to provide care and caring for the care recipient.

Kittay’s (1999) view of nested dependencies entails a political obligation to support the care provider in meeting their care obligations to the care recipient. Yet, it appears that this generates some complications. Is it reasonable for the care provider to experience
at least some distress in order to meet their care obligations? What guidance does it offer for meeting these obligations? How might differences of opinion be resolved? At first blush, this appears to put some pressure on the idea that the ethics of care is better equipped than other views to attend to such ethically challenging situations.

Nonetheless, it is too quick an assessment to conclude that the ethics of care is therefore inadequate. The ethics of care, though practical in its outlook, does not aim to provide a framework to guide action. So to judge it as such is to measure the ethics of care against a standard to which it is opposed.

6.3.3 JUSTICE AND DECISION-MAKING FROM THE ETHICS OF CARE PERSPECTIVE

When faced with a scenario such as the one described above, people from an ethics of care perspective, rather than trying to simplify the story, will often be more interested in the details that enable an understanding of context. Instead of trying to sharpen the horns of the dilemma, an alternative solution is sought; a way out of the problem such as through a compromise. As pointed out by Noddings (1984: 96):

‘Faced with a hypothetical moral dilemma, women often ask for more information. It is not the case, certainly, that women cannot arrange principles hierarchically and derive conclusions logically. It is more likely that they see this process as peripheral to or even irrelevant to moral conduct. They want more information, I think, in order to form a picture…. Moral decisions are, after all, made in situations; they are qualitatively different from the solution of geometry problems.’

Putting aside the gendered description, already criticised above, the process of ‘forming a picture’ is nevertheless a central part of how the ethics of care approaches ethical problems. Edwards (2009) sees the benefit of this when he argues that having a care-infused approach to ethical thinking can help the care provider to be more emotionally receptive rather than just following ethical principles in a disinterested way.

Yet, for Edwards, principlism still dominates and ultimately he argues that this is required to make sound ethical decisions. This view is compatible with what Edwards (2009:174) describes as the ‘third wave’ of the ethics of care. Here, care is seen as more of an orientation or matrix within which ethical decision-making can take place rather than being sufficient as a basis for an ethical theory itself. Vanlaere and Gastmans
(2011) take a similar view employing personalism to bolster the normativity of the ethics of care.

It is worth noting that these combination approaches differ from the one proposed by Slote for ethics of care and virtue ethics. For Slote, these two concepts are *connected* through the virtue of receptivity; whereas Edwards argues that care ethics *requires* the additional theory of principlism in order for it to be normatively viable.

In contrast, Tronto (1995; 1993) emphasises care not so much as a matrix or orientation that needs to rely on further theories, but as something that has the potential to be central in a reconstruction of our moral and political life. In a similar vein to Kittay, she argues that our shared need for care points to justice and a *political theory of care* in order that care can reach its full potential.

‘To address and to correct the problems with care... requires a concept of justice, a democratic and open opportunity for discussion, and more equal access to power. An ethic of care remains incomplete without a political theory of care.’ (Tronto 1993: 155)

As discussed above, the injustice for many care providers has a political dimension. Held (2005: 68) also develops the idea of ’meshing’ care and justice. Held states that in the past she tried to assign care and justice to different roles in ethical thinking however:

‘I now think that caring relations should form the wider moral framework into which justice should be fitted.’ (Held 2005: 71)

To explain why Held (2005: 71-72) takes a line that is similar to Kittay’s:

‘Though justice is surely among the most important moral values, much life has gone on without it.... Without care, however, there would be no persons to respect and no families to improve.’

Slote (2013: 106) also see justice as being integrated into an ethics of care approach.

‘I have long argued that a care ethics that seeks to be a general approach to moral questions needs to take on issues of justice *but deal with them in its own distinctive care-ethical/sentimentalist terms.*’ [Original emphasis]

Held (2005) suggests that the overall moral design of feminist moral theory is based on caring relations and cannot be reduced to elements such as utility, justice or virtue. Here there is a distinction with Slote as Held is critical of the fact that he does not place
relationships at the centre, instead favouring an agent-based sentimentalist virtue ethics.

The ethics of care analysis rather than taking a virtue or morality first (Tronto 1993: 7) approach, requires instead that the whole picture is seen. An essential part of that picture is the social and political situation of the care provider in relation to the care recipient. The ethics of care approach is opposed to the idea of trying to get a solution to an ethical problem by factoring out this background. Also it is opposed to seeing such dilemmas as single events isolated in time. Instead, solutions are sought in a broad sense both in terms of context and time. Decisions need to be made, not just by the individual participants in this one dilemma but by society as whole and these will then support and inform others who face similar dilemmas in the future.

6.4 APPLYING THE ETHICS OF CARE TO DEMENTIA CARE

So rather than focusing in a reductionist way on a particular question such as "should the care provider tell the truth", the relevant concerns for an ethics of care analysis are much broader in scope. Drawing on the work of this chapter, here are some possible questions that might arise:

- What is the context of the relationship between the care provider and recipient?
- What do both people feel about the situation?
- Which courses of action might allow for both care providers and recipients to feel fairly treated and cared for?
- How might the political or social situation be changed to alleviate difficult situations like this in the future?

So let’s now reapply to the example above. Firstly, it is not clear what the relationship is between the care provider and the woman, Jane, with dementia. Is it someone that Jane might recognise or trust? It may be assumed that the care provider is an employee, though this may not be the case. Nonetheless, it seems reasonable to try and find someone who has a positive relationship with Jane. Memory loss may hinder this process, but it is still valid for the care provider to ask if he or she is the best person available to engage with the woman at this time.
The second question considers the emotions being felt by both people concerned. The example is clear that Jane is distressed, however, the nature of that distress is not made clear. Is it anger, sadness, frustration? It seems reasonable to state that these emotions may inform differing care responses. Anger might require calming; sadness, comfort; frustration, action. The question here is whether this also informs a differing ethical response.

The ethics of care would suggest that the care provider needs to feel their way through in order to respond to the complex reality of the situation. Here receptivity can be employed to respond empathically and with flexibility (Slote 2015; Slote 2013; Noddings 1984). Recall, Slote’s key point above that receptive people are able to judge ethical situations based on the amount of warmth that is expressed by the interaction. There is also a great deal of similarity with the perspective of Julian Hughes (2013) as outlined in his article ‘I’ feel me?’ How do we understand the person with dementia? which employs the work of Wittgenstein:

‘...the foundations for good care emphasise the importance of knowing the people we care for in as holistic a fashion as possible. We are back to ‘being with’ as a priority before ‘doing to’. And we are back to the importance of the intuitive, the expert clinical judgement based on feelings akin to an aesthetic sense of what is right.’ (Hughes 2013: 356)

This quote was used in Chapter 4 (4.9.1). Here it was pointed out that this approach is more suited to an ethical model that is less rigid and therefore does not seek to produce answers based merely on the outcome of a reasoning process. Such a strategy is more plausible in the context of an ethics of care. As part of this broader picture, feelings have a place and they may form part of this ‘aesthetic sense of what is right’.

So, the ethics of care suggests that the care provider must also work within what feels acceptable for him or her in order for the care to be ethical in this wider context. This links to the third question that asks which course of action might allow both care providers and recipients to feel justly treated and cared for. Here the idea of mutuality expressed as doula is brought into focus. Whether the decision is made to tell the truth or not, this needs to be done in a way that supports the care provider and the care recipient.
The discussion that has run through previous chapters has highlighted there are competing answers in this situation, and it should be accepted that there will be a certain amount of blameless diversity (Garrett 2015) in the judgements reached. This may be due to there being insufficient information available and with this an answer might become clear. However, more information would not satisfy someone who holds the view that the truth should always be told. If someone with this view is best placed to care for the woman, then doula would suggest that everyone should be supported to deal with the distress that the scenario suggests this would cause. Furthermore, being receptive to this distress may ultimately enable the care provider to reconsider her fixed position.

This leads to the final question which asks if there are any political or social changes that can help alleviate the problem. It may be that Jane’s care providers would be able to provide better care in a different environment or with improved resources in the current environment. It is important in terms of justice that every effort is made for Jane’s preference to be heard in terms of what would improve her current living situation. Based on Tronto’s (1993) work, Brannelly (2011; 2006) argues that incorporating the ethics of care into dementia care can enable care providers to take an approach of negotiation with care receivers to solve problems, which in turn promotes the notion of citizenship.

In summary, those who hope to find an ethical framework in the form of prescriptive guidance or a decision-making flowchart will be disappointed by the ethics of care approach. Instead we are expected to dig deeply to respond intuitively to these human dilemmas.

6.5 EVALUATING THE ETHICS OF CARE FOR DEMENTIA AND THE POSSIBLE ROLE OF VIRTUE ETHICS WITHIN IT

6.5.1 THE ROLE OF EMOTION

John Paley (2011; 2002) argues that the notion that the ethics of care can rely on emotion alone is flawed:

‘Either you feel sympathy, or you don’t; and if you don’t, how can the “ethics of care” make any moral demand on you? What, indeed, is the point of an ethic that
appeals only to people of a certain cast of mind and which, in any case, recommends what they are naturally inclined to do without prompting?’ (Paley 2002: 140)

As has been shown, some ethics of care theorists have argued that we have an obligation to care for particular others and that society must support us to meet our obligations. It is the source of this obligation that is at issue here, as Paley argues that the ethics of care can make no demand on a person if they feel no sympathy. Paley's (2002) concern leads him to propose the idea of a Kantian ethics of care. Through this he argues that it is possible to reconcile the reason-based morality of Kant with the emotion-based ethics of care. Paley also states clearly that if Kantian duty (based in autonomy) and sympathy conflict then it is the former that must take precedence.

‘In cases of conflict, when the sympathetic impulse clashes with what morality requires, duty takes precedence; but, generally speaking, there is no reason to think – and Kant does not suggest – that ‘inclination’ and duty are, motivationally, in competition’ (Paley 2002: 140)

However, Paley’s argument for the compatibility of ethics of care and the Kantian moral law relies on the seemly optimistic idea that it is a rare event for inclination and Kantian duty to conflict. This claim is somewhat extraordinary as contemporary ethical debate often focuses on dilemmas where duty and inclinations conflict, not least with the example where telling the truth (a Kantian duty) conflicts with an inclination to avoid distress.

Returning to the work of Slote, he takes a different approach to this problem arguing that empathic concern for others leads most people to wish to do something to alleviate suffering. Not doing so is wrong if

‘...an act one performs reflects or exhibits a lack of fully developed empathic caringness.’ (Slote 2007: 32)

What makes the act wrong is not that one has failed to meet an obligation based in autonomy. Instead it appeals to the idea of how a fully developed empathically caring person would respond to someone suffering. The obligation is therefore to avoid conduct that a fully empathic person would also avoid; which in this case means not being indifferent towards someone’s suffering. As this obligation is a minimum, there is
also room for actions above and beyond these obligations for those who wish to act from an even higher degree of empathic concern.

As discussed, the idea of being an empathic caring person is developed in later work by Slote (2015; 2013) to be seen part of a virtue of receptivity. Unlike Paley, Slote does not hope for a correlation between emotion and rationality. As this quote suggests, for Slote and other sentimentalists, it is our emotional responses that we find morally pleasing in human beings, not their rational capabilities.

‘The wife-saving husband who acts and/or needs to act from moral duty is less morally attractive than one who acts from love of and concern for his wife, and such love and concern, far from rendering us or morality less dignified, actually make it more humanly appealing and heart warming. Or so at least the care ethicist thinks.’ (Slote 2013: 130)

So in answer to Paley’s original question of how the ethics of care can make a demand on the unsympathetic; the beginnings of an answer can be found. Being receptive in the way described above is something that is seen as admirable (or morally attractive) by other receptive people. So rather than suggesting that the unsympathetic person acts from reason to make up for their deficit, the ‘demand’ would be to cultivate receptive empathy; or, if this is not possible, emulate someone who has and then act accordingly. This is not to say that reason doesn’t have a role in ethical decision-making. The argument here is that reason needs to serve someone in their quest for good character; not dictate what that good character ought to be.

The overall strategy of the ethics of care of bringing emotions, relationships, practical decision-making and political justice to the fore appears to be both defensible and a sound fit for dementia care ethics. However, there are two main issues with the ethics of care that remain to be tackled: an apparent tendency for paternalism and whether it can generate normativity.

### 6.5.2 PATERNALISM REVISITED

As Tronto (1993) recognises, there is a danger in care that those who provide it believe that they have a better idea of how to meet someone’s needs than the care recipient. If these acts are then carried out against someone’s wishes, it is paternalism. (Dworkin 1988)
Currently, a culture of paternalism is considered to be a problem in dementia care. As a recent review by the House of Lords into the implementation of the Mental Capacity Act states:

A fundamental change of attitudes among professionals is needed in order to move from protection and paternalism to enablement and empowerment. (House of Lords 2014: 8)

Previous discussion of paternalism in Chapter 2 (2.5) focussed on respecting autonomy as a way of preventing hard paternalism, where the individual’s wishes are considered voluntary and adequately informed. However, there were barriers to establishing autonomy for those with more severe dementia. Paternalism, on the other hand, can call on beneficence, the idea that it is necessary to act in a way that provides benefits and lessens harm when the care recipient lacks mental capacity (Beauchamp and Childress 2013).

Though, calling on the ideas of autonomy and beneficence as balancing principles is not considered to be a standard part of the ethics of care, both autonomy and beneficence can claim a place in the tradition.

The ethics of care understands autonomy relationally rather than individualistically. However, as outlined above, this can lead to paternalism as these relational forces may themselves become paternalistic by overwhelming the individual, or (conversely) there may be paternalism due to the need to override a choice made under oppressive social forces.

Benevolence as the ground for beneficent actions also has a more controversial position in the ethics of care. Slote in his earlier work (Slote 2001) focussed on benevolence as the basis for an agent-based virtue ethics for caring, drawing on the philosophical background of Hutcheson and Hume. Slote’s early focus draws criticism from Held (2005) who stated that benevolence is not enough and that sensitivity is also required. This deficit is arguably corrected in later work by Slote’s move to receptivity as the main value via the notion of empathy (Slote 2007; 2013).

The point at issue here is whether a shift to promoting receptivity in care providers helps answer the concern about paternalism. For Slote, being receptive means being sensitive to others’ views (Slote 2013). As mentioned, receptivity is also part of the
work of Noddings (1984), and appears similar to the notion of attentiveness which forms an element of an ethics of care for Tronto (1993). It is fair to the say that paternalism by definition involves a lack of sensitivity to others’ feelings and preferences, or at least a lack of will to respond to them. Receptivity would involve having a greater sensitivity for others’ feelings and preferences. So a reasonable claim can be made that receptivity is an antidote to any paternalistic tendencies in the ethics of care.

As a result, it is possible that someone with receptivity may avoid a beneficent action, if they are sensitive to the feelings of the individual who is opposed to this action. It raises the question of whether this is merely therefore respecting autonomy through another route. However, as outlined, the arguments that would support autonomy in this sense are based in the ability of the individual with dementia to reason. Here it is not (necessarily) reason that is driving the decision. Instead, what makes the decision a good one is based on trust in the judgement of the care provider. It is the trust in the care provider’s ability to be sensitive to the care receiver feeling wronged by what others consider to be the beneficent action. Ultimately we are back to the idea that this relies on a virtue in the care provider that they can make these intuitive or aesthetic moral judgments.

6.5.3 THE NORMATIVITY PROBLEM

For some scholars, the ethics of care approach raises a normativity problem. The discussion so far in this chapter suggests some solutions. It could be argued that the ethics of care simply does not recognise that normativity is necessary. As discussed, the ethics of care expects each situation to be different and therefore does not seek rules to guide conduct. Tronto (1993) though, clear in her wish to distance herself from moral relativism, nonetheless argues that different judgements are required for people in differing situations.

Kittay, on the other hand, does wish to appeal to the normative force of vulnerability-responsive obligations based in personhood. However, this is grounded in the notion of moral status based on being a mother’s child. Being a mother’s child makes every human being worthy of care. This seems to open to the same objections as those raised by idea of moral status being based in humanness alone. Instead, it is argued here that
there is a place for a combination approach in order that challenges to normativity can be met.

Paley's (2002) suggestion of a Kantian ethics of care requires the seemingly optimistic assumption that inclination and Kantian duty are usually aligned. Also, as a Kantian view, it would exclude some people with dementia from full moral consideration. A care provider following such a view would be unable to respect a non-autonomous individual with dementia as a person and would therefore prioritise others over that individual. Edwards (2009) model of principles infused with care is a promising candidate as it balances out an uncompromising reliance on autonomy. The role of principles is yet to be fully assessed, so this will be returned to in the next chapter.

The arguments in this chapter and the previous ones have so far suggested that Slote’s approach of seeking a connection between virtue ethics and the ethics of care is a sound fit. Virtue ethics can help to answer the normativity problem in the ethics of care. The virtue of receptivity along with other virtues can be aspired to, and doing this is approved of by other receptive individuals. So there is no need to assume that inclination and duty based in reason are usually aligned. This virtue ethics approach seeks to ground our response in the emotions felt by the receptive individual. The normativity comes from the approval or warmth felt by other receptive individuals.

6.6 CONCLUSION

This chapter has argued that the ethics of care has a number of benefits as a philosophical approach to ground an ethical model for dementia care. One of these is its emphasis on the broader context of ethical decision-making. Rather than taking a reductionist analysis of ethical challenging situations by merely simplifying the situation and factoring out the variables; the ethics of care engages with the wider picture drawing on sociopolitical context and wider information about the people involved.

This analysis means that every ethically challenging situation is treated differently. Similar situations, which might be simplified in order to appear the same for some philosophical approaches, will actually have different outcomes under an ethics of care depending on these variables. So, in the example of a truth-telling dilemma, it is not the
question of whether it is always right to tell the truth in similar circumstances but a subtler judgement based on feelings, relationship and social context in this particular situation, at this time.

The ethics of care perspective also looks to the sociopolitical background in an effort to ascertain what can be done to prevent or alleviate such dilemmas in the future. Overall, it is proposed that engaging with ethical problems in this way produces solutions to dilemmas which remain invisible from a more myopic moral perspective.

Yet, there are some pitfalls with the ethics of care. Firstly, some versions seek to place an obligation on people to provide care if they find themselves in the situation of having responsibility for a particularly vulnerable individual. As a result, care providers may find themselves overly burdened, and this responsibility appears to fall more heavily on certain groups in society. In response, it is argued that any felt obligation to care must be balanced with the idea of mutuality and recognition of political justice in caring. Both care providers and care receivers need to be supported by society in order for ethical care to result. Care work needs to valued and seen as a concern for society as whole. It is not merely a private arrangement between individuals.

Secondly, the tendency in the ethics of care to base ethical decisions on relationships and social context is two edged. It is agreed here that relationships are necessary for care. However, the social forces in which relationships are formed can be overpowering. This may result in a culture of paternalism/maternalism or more malevolent outcomes that care providers or receivers are not empowered to challenge. It is argued here that promoting receptivity in care providers helps answer this concern, as being receptive means being sensitive to the feelings and views of others rather than merely pursuing a belief that one can empirically know how best to promote someone’s welfare. As such, paternalism and malignant social conditions can be challenged by people being receptive in this way. For this to work, the emphasis needs to be on the character of care providers being receptive within a supportive sociopolitical environment.

Finally, the role of emotion in the ethics of care has been evaluated. The chapter has argued that emotions form a central place in dementia care. However, the ability of emotions to provide a normative foundation for ethical behaviour has been challenged. The objection was raised that some people may be indifferent or have feelings that are
not conducive to ethical conduct and in this situation an ethics of care can make no claim on them to go against such feelings.

Instead, it is concluded here that individual emotions are an important guide for conduct. However, this must be backed by the evaluation that some emotions are more praiseworthy than others depending on the situation. For Slote, this judgement is better made by people who have developed a virtue of receptivity. The background to this is that emotions are considered praiseworthy only if they generate actions that then produce a sense of ‘warmth’ in others who are receptive. (Slote 2013:200). As such, the ethics of care should be interpreted in a manner that connects it to virtue ethics.
7 BALANCING PRINCIPLES AND INTERESTS

7.1 INTRODUCTION

The previous chapter concluded that the ethics of care is a promising philosophical approach to ground an ethical model for dementia care. In this context, it was suggested that the ethics of care is best understood as a sociopolitical theory that places a responsibility on society to support good care. It also introduced a different way of approaching ethically challenging situations. Instead of taking a reductionist approach, a broader account of these situations is sought. The rationale being that a wider picture can help to find solutions that may not otherwise be visible.

It was also advanced that the ethics of care should be interpreted in a manner that connects it to a virtue of receptivity in the care provider as outlined by Slote (2013). It was argued that this connection can be made by promoting receptivity as a foundation for the character of care providers. This, in turn, promotes ethical care by those caring being both sensitive to and identifying with the feelings and views of the individual being cared for. This virtue ethics foundation helps answer a number of objections that can be raised against the ethics of care, such as that it places too heavy a burden on care providers, its lack of normativity and its tendency to be paternalistic.

Recent chapters have moved away from primarily focussing on the moral status of the care receiver. An attempt to reintroduce the notion of a care-based moral status grounded on being a mother's child (Kittay 2009; 1999) was also found philosophically unconvincing. Overall, this move away from moral status removes the difficulties highlighted in finding an adequate ground for personhood when dementia is severe. Nonetheless, this shift in emphasis has not been intended to remove the care receiver from the picture. After all, it is not possible that someone could care in a receptive way without having consideration for the receiver of care.

The ethics of care suggests that care providers need to feel their way through complex situations in order to respond appropriately. As such, the emotions felt by receptive individuals by putting themselves in the position of others are an important guide to conduct. The care receiver is linked in the ethical picture with the care provider in a shared sociopolitical environment. Furthermore, understanding if a care provider has
responded in a good way is reliant on the approval of other receptive individuals and is therefore not a notion that is merely *internal* to the care provider.

Yet, taking an approach that relies solely on the feelings of the care provider, even when these are grounded by approval of a receptive character may not be sufficient. Arguments can still be put that in order to respond to the competing ethical demands brought by multifaceted situations, a rational thinking procedure is required. There are times when factors such as respecting autonomy and ensuring that things go best overall might well be relevant. It is *not* being proposed that these determine the outcome absolutely, just that such considerations might be part of the thinking of a receptive care provider when ascertaining which options are acceptable or better.

So, this chapter will consider the use of frameworks which balance relevant principles and interests, and to assess whether such frameworks might be compatible with the ethical approach argued for above. The factors involved in balancing are ones that have already been discussed. However, they are being returned to now in a somewhat different context as they are being employed together in the context of a pluralistic model.

In this context, it will initially explore the influential biomedical ethical framework, the principlist approach of Beauchamp and Childress (2013). It will investigate their claim that this framework reflects a common morality, before moving to apply it to an example. The care infused principles approach of Edwards (2009) will also be evaluated.

The investigation will then move on to examine whether it is possible to structure decision-making around a consideration of interests of the individuals involved. This section will assess whether responding to interests can allay any concerns brought by the move away from basing the decision-making framework on the moral status of personhood. In order to do this, the discussion will begin with Singer's (2011) principle of equal consideration of interests and this will be contrasted with the ethics of care approach already discussed. The chapter will then move on to discuss the central role played by interests in the Nuffield Council on Bioethics Report before exploring the concept of best interests.
The notion that the best outcome might be known moves the discussion onto the role that consequentialism might play. Consequentialism requires the maximising of good outcomes without consideration of the moral content of the actions that produce the outcome. Forms which appeal to the maximising of a single good offer an appealingly simple alternative to pluralism by measuring the amount of this good that results from following the competing outcomes.

A critique of this then leads to a consideration of rule consequentialism and the intriguing proposal of Parfit (2011) that this can be combined with a Kantian form of contractualism to produce a Triple Theory. Based on the work of earlier chapters, this brings the possibility of a combined model drawing together the contemporary work of Slote (2013) and Parfit (2011) along with the Beauchamp and Childress (2013). The viability of this will be assessed before moving to a conclusion.

7.2 PRINCIPALISM

7.2.1 THE COMMON MORALITY AND MORAL PLURALISM

The four principles approach of Beauchamp and Childress (2013) is a well-established ethical framework in the bioethical field. It was first conceived in the late 1970s and was a clinical development of the Belmont Report (1979) into research ethics that had similar principles and was also authored by Tom Beauchamp.

The four principles are reproduced here along with Beauchamp and Childress’s (2013:13) explanations of each principle:

‘(1) respect for autonomy (a norm respecting and supporting autonomous decisions), (2) nonmaleficence (a norm of avoiding the causation of harm), (3) beneficence (a group of norms pertaining to relieving, lessening, or preventing harm and providing benefits and balances benefits against risks and costs), (4) justice (a group of norms for fairly distributing benefits, risks and costs).’

The idea follows that these four principles can be applied to ethically challenging situations in order to inform judgements and formulate rules. For Beauchamp and Childress (2013, p13) these principles function as:

‘...an analytical framework of general norms derived from the common morality that form a suitable starting point for biomedical ethics.’ [my emphasis]
As can be seen, the idea of a common morality forms a starting point for philosophical grounding of the principles. This assumes that there is a ‘set of universal norms shared by all persons committed to morality’ (Beauchamp and Childress 2013: 3). To illustrate this, Beauchamp and Childress give a number of examples of the sort of norms they have in mind such as those that forbid killing, stealing and causing pain; along with those that instruct persons to tell the truth, keep promises, rescue people in danger.

They draw on three possible justifications for the claim that the common morality exists. Firstly, there is the possibility of an empirical justification, which aims to gather evidence that this is indeed what the people committed to morality universally believe. However, the empirical investigation required to justify such a claim has not been carried out leaving Beauchamp and Childress (2013: 416) merely to propose it as a hypothesis.

‘If an empirical investigation were to show that a universal content is found in moral belief, the claim a common morality exists would be empirically justified.’

However, if such an empirical investigation was possible and it found the hypothesis to be true, it could still be challenged. Possible challenges might include whether the results might change over time, whether the study can satisfactorily eliminate bias and error and whether the sample could ever be diverse enough to justify the claim of universal content. Moreover, Beauchamp and Childress themselves recognise that an empirical justification would not be sufficient to justify their claims; instead they look also to normative and conceptual justifications.

For Beauchamp and Childress (2013: 383), the four principles approach is consistent with a wide range of normative ethical theories:

‘Many and perhaps most moral theories lead to the acceptance of the action guides we present... These theories defend roughly the same principles, obligations, rights, responsibilities, virtues, and the like.’

So, Beauchamp and Childress see principlism as consistent with a convergence of ethical theories. However, they point out that this convergence, on its own, does not justify the principles or the common morality from which they are drawn; it is necessary for the ethical theories themselves to have their own justification.
‘Our conclusion... is merely that such theories have been and can be constructed and, if they are successful, they would justify the norms of the common morality’ (Beauchamp and Childress 2013: 420)

For Beauchamp and Childress, a more promising avenue is the conceptual justification of the common morality sought in the (seemingly Kantian) idea that in order for morality to exist there needs to be a set of norms that everyone shares. This means that to claim something is moral when it lies outside the common morality is therefore ‘conceptually mistaken’ (Beauchamp and Childress 2013: 420). Beauchamp and Childress appear to be arguing that the very idea of morality infers the existence of common morality norms.

Having argued for the existence of the common morality on these terms, Beauchamp and Childress then use it as a basis from which to draw their four principles. They argue that the common morality, by definition, cannot be pluralistic as it cannot have norms that are relative to individuals or cultures; however, the four principles approach is pluralistic in the sense that it draws on four non-absolute principles while remaining objectivist in the sense that the result of applying these principles must reflect the objective common morality.

As was highlighted in Chapter 3 (3.3), the four principles approach draws extensively from the work of WD Ross (1930) who argued for prima facie (not absolute) duties. As part of this, Ross (1930: 21-23) proposes prime facie duties of beneficence, non-maleficence and justice. Interestingly, considering its contemporary importance, the principle of respect for autonomy has no direct equivalent in Ross; though elements can be found in his proposal of prima facie duties of fidelity, to which he also adds duties of reparation and gratitude.

Ross (1930) argues that underlying the approach of prima-facie duties there is a duty proper which is objective but hard to determine. The aim of the prima facie duties of Ross and the principles of Beauchamp and Childress is to lead us to the morally right solution which is only indirectly knowable.

Beauchamp and Childress appear to take this pluralist approach a step further by claiming also that the domain of character ethics is equal and consistent with the principalist approach.
‘Virtues, ideals, and aspirations of moral excellence support and enrich the rights, principles and rules discussed in Chapter 1. There is no reason to consider one domain inferior to or derivative from the other, and there is reason to believe that these categories all have a significant place in the common morality’ (Beauchamp and Childress 2013: 56)

As Beauchamp and Childress place the ethics of care under the category of virtue ethics, it follows from this that they argue for compatibility between the ethics of care and the principlist approach.

‘We need not reject principles of obligation in favour of virtues of caring, and we can conceive moral judgements as involving moral skills beyond those of specifying and balancing general principles.’ (Beauchamp and Childress 2013: 37)

Beauchamp and Childress’s seminal work devotes one chapter to moral character and there is a brief discussion on caring and the ethics of care. Yet, they offer little argument as to how the virtues and principles might work together outside of providing a table that gives equivalent virtues to each of the principles (e.g. benevolence and beneficence).

From the other side of the divide, the ethics of care, as highlighted, is hostile to the idea of analysing matters in the reductionist terms of principles seeing them as, at best, peripheral to moral conduct (Noddings 1984). Nonetheless, Edwards (2009:176) aims to draw on interpretations of the ethics of care which are more compatible with principlism in order recommend a ‘principles infused with care’ approach.

7.2.2 EDWARD’S PRINCIPLES INFUSED WITH CARE APPROACH

A good way to begin to illustrate this approach is to draw on an example from Edward’s own work.

‘…a patient who, in a nurse’s considered view, is in urgent need of pressure-area care, competently refuses such care. Suppose two nurses – call them nurse A and Nurse B – have been introduced to the rudiments of the principle-based approach….’ (Edwards 2009:177)

Nurse A applies the approach and decides that due to respect for autonomy (a moral norm that respects and supports autonomous decisions) this refusal needs to be respected.
Nurse B, on the other hand, does not take the refusal at face value. Instead Nurse B ‘would try to enter into a dialogue with the patient’ the aim being to elicit if there was ‘anything that was of concern to him.’ (p177) If the patient has fears that can be allayed then they may agree after all to the intervention. On the other hand, the patient may not have any fears, or they might continue to refuse treatment despite having any fears allayed. In this case, Nurse B would also respect the autonomous decision of the patient.

Edwards favours the approach of Nurse B and sees this as a way of avoiding the accusation that the principle-based approach ‘fosters a callous and uncaring attitude.’ (Edwards 2009: 178).

Both nurses appear to be respecting autonomy in the sense understood by Beauchamp and Childress. However, their responses can be differentiated by proposing that Nurse B is actually taking a more relational view of autonomy. Employing relational autonomy would also mean not taking the initial refusal at face value; instead, the importance of relationships and context would be taken on board in this more care-focussed approach.

Yet Nurse B’s approach is not immune from criticism. Let’s say that Nurse B feels under pressure to persuade the patient as she is concerned that to do otherwise would make it appear that she is not able to perform her duties as a nurse. So Nurse B listens to the fears but is able to dismiss each one in order that she can do what is felt to be best for the patient. Now, what might have appeared to be a caring act of allaying fears, can instead be seen as an intervention to elicit agreement from the patient. The relationship, rather than fostering true autonomy, actually becomes a vehicle for paternalism/maternalism. It was this paternalistic tendency in care ethics that lead the previous chapter to call on virtues in the care provider in order to diminish this possible effect. The hope was that a carer who takes time to cultivate caring virtues in their character would be one who was receptive to the both the fears and opinions of the care receiver, rather than merely pursuing the intervention that the carer believes is in the best interests of the patient.

On the other hand, this could be overly critical. As pointed out, both nurses wish to follow the four principles as a way of carrying out the common morality. It also appears that both nurses are committed to the first principle; the difference is one of strategy in application. It seems reasonable to imagine that Nurse A and Nurse B could replay the
argument above and a course of action that reflects the common morality could result from this.

It has already been stated above that Beauchamp and Childress (2013: 37) are sympathetic to the idea of having ‘moral skills beyond those of specifying and balancing general principles’ even though these are not reflected fully in their framework. The ability to engage the patient in a caring conversation in order to better to understand their views could be seen as part of the moral skills to which Beauchamp and Childress refer.

So, ultimately, having care infused principles is a useful application of the four principles approach. It also shows how principlism can be compatible with perspectives such as the ethics of care, pointing the way to a more pluralistic approach.

7.2.3 APPLICATION OF THE FOUR PRINCIPLES TO DEMENTIA CARE

In the introduction, it was suggested that there are times when a more structured approach may be required in order to assist with making a decision. Attention will now turn to why this might be, initially by illustration with an example:

Mrs X lived with her daughter and her family and used to take a lot of pleasure in cooking family meals whilst everyone was at work or school. When her dementia progressed she started leaving the gas stove on for long periods of time and there were a few near misses when care providers visiting Mrs X found the house full of smoke. The daughter in consultation with the other care providers decided to switch the gas off before leaving for work in the morning. However, Mrs X became deeply distressed as she still tried to cook dinners but could not understand why it would not work. She started to lose her appetite and did not eat the ready meals that were brought by the care providers.³

A care provider faced with such a situation may struggle to work out the best course of action. Both the professional care provider and the daughter are rightfully concerned about a catastrophic outcome. It seems that fire or explosion is likely due to the fact there have been several near misses. However, Mrs X is deeply distressed and it seems a

³ Thank you to Egle Vatkeviciute for this example from her practice.
rather uncaring (and unreceptive) act to deny her the pleasure of cooking for her family as she has always done.

However, it may not be immediately obvious how an expectation to act as a receptive care provider can, on its own, provide the overt guidance necessary to tackle such a dilemma. The four principles approach may well provide some acceptable options to work from:

Firstly, autonomy. Mrs X has a long standing wish to cook for her family that has continued as her dementia has developed. It appears that this is an autonomous wish that has endured. Furthermore, she will have the prima-facie right to be told the truth about why the gas has been switched off if it is established that Mrs X. has autonomous personhood.

Secondly, non-maleficence. It could be argued that the act of turning off the gas causes harm to Mrs X. This is based on the definition of harm outlined by Beauchamp and Childress (2013: 153)

'A harm is a thwarting, defeating, or setting back of some party's interest'

However, Beauchamp and Childress (2013: 153) go on to point out that this along with the others is a prima-facie principle

'Harmful actions that involve justifiable setbacks to another's interests are not wrong.'

So it is possible for a greater consideration for health and safety to overrule this second principle and still be consistent with the overall duty or common morality.

The third principle, beneficence, is also engaged as in one formation it states that

'One ought to prevent evil or harm' (Beauchamp and Childress 2013: 152)

This addresses what for the care providers may well be their central concern. The paternalistic act of preventing the great harm of a fire or a gas explosion can be justified under the principle of beneficence. So their course of action is justifiable. However, this leaves the autonomy of Mrs X (if this can be established) unmet. However, as the story continues it can be seen that a solution could be found.
Mrs X experienced a serious deterioration of her emotional and physical well-being after the gas was switched off during the day. This in turn caused the daughter and the professional care providers to feel sad for her in this situation. As a result of this the daughter upgraded the care package and Mrs X had professional care providers three times a week to help her cook lunch and enjoy family meals again.

By spending extra money on supplementary care, the receptive attitude of the daughter and the care providers meant that they performed an action that might be considered supererogatory by some views as the daughter did more than fulfilling her duty to keep her mother safe. However, this is arguable as it may well be considered a duty to pay for this extra care under a principle of beneficence in order to relieve her distress at having the gas switched off. It also meets the principle of respecting an autonomous wish to cook, if this can be established to be present. In this sense, the decision reflects the four principles approach. Nonetheless, it also reflects an ethics of care approach in that it looks at a compromise in order to try and remove the dilemma through finding a practical alternative.

Yet, there is a possible fly in the ointment as this proposed solution also engages the fourth principle of justice. The principle of justice as outlined by Beauchamp and Childress (2013) would argue that Mrs X should not get more than her fair allocation of resources. Dementia care requires increasing amounts of resources as the numbers with the condition increase. As such the amount of care available is subject to rationing. It is possible that the daughter’s decision to pay for extra care could result in other people receiving less of this resource due to there being less available overall. Even if there are enough carers to provide the extra care, it might still be argued that it is unfair that Mrs X gets a higher level of provision merely due to her daughter’s ability to pay.

Yet this view can be mitigated (at least in the long term) by the ethics of care perspective. Recall, that an essential part of the ethics of care, as argued above, was a sociopolitical argument to value care by providing support for those who provide and receive it. This would mean a reorientation of society’s values to ensure there is enough caring resource and that it is available to everyone who requires it.
So it seems that the four principles have a viable place in dementia care ethics, at least as a *decision-making* tool. As such, it can be seen as forming a viable element of a broader ethical model.

7.2.4 WEIGHING AND BALANCING OF THE FOUR PRINCIPLES

As raised above, Beauchamp and Childress (2013) philosophically ground their work with the proposal that seemingly diverse philosophical perspectives are in fact compatible and actually aiming at the same common morality. At face value this idea is an appealing one and such an idea has been suggested by Derek Parfit to be the case for consequentialists and Kantians who he describes as ‘climbing the same mountain on different sides’ (Parfit 2011: 419)

Yet, if this idea is to be accepted, then it is important that a common morality is one that is inclusive of people with dementia. Beauchamp and Childress’ approach certainly owes a significant debt to deontological views and these views have a tendency to degrade the moral status of people with dementia. The principle of respect for autonomy relies heavily on how autonomy is understood. Beauchamp and Childress themselves take a view of the concept that is likely to exclude at least some people with dementia.

The nature of the four principles framework allows other aspects to be engaged in an effort to be more inclusive. Nonetheless a lot, if not everything, rides on how the *individual with the decision-making power* actually weighs and balances these principles. Beauchamp and Childress (2013: 20) give the following explanation of weighing and balancing in terms of their four principles framework:

> ‘Balancing is the process of finding reasons to support beliefs about which moral norms should prevail. Balancing is concerned with the relative weights and strengths of different moral norms... Accordingly, balancing consists of *deliberation and judgement* about these weights and strengths.’ [my emphasis]

The process of deliberation and judgement needs to be supported by good reasons, though they also suggest that ‘intuitive balancing is one form of balancing.’ (Beauchamp and Childress 2013: 20). In order to ‘allay concerns’ (p22) about the model being too intuitive they offer a number of conditions that need to met in order to justify infringing one prima facie norm in order to adhere to another. These conditions suggest that good
reasons need to be given for overriding a norm in order that the moral objective can be achieved; that it can be justified and done with the lowest level of infringement of the norm overridden.

It is worth noting that this strategy of constrained balancing can be used to justify hard paternalism, where a fully voluntary and informed choice is overruled. However, this is only allowable in Beauchamp and Childress's (2013: 222) view if the patient is at risk of 'significant' harm, which the paternalistic action will 'probably prevent'; there is no 'morally better' alternative and the 'least autonomy-restrictive alternative' is adopted.

In the process of deliberation about the right course of action, Beauchamp and Childress (2013:22) concede that disagreements between ‘morally committed persons’ may persist. This seems to put some pressure on the idea of a common morality. Furthermore, it seems to be analogous, if not the same, as debates that occur between people who have different theoretical positions in ethical discourse more generally. The four principles may act as a good way of describing or categorising these debates but it cannot be expected to resolve them.

The four principles can be weighed and balanced, but they will be weighed and balanced by different people differently. The key factor in weighing may well be the character of the people who perform the weighing. The example above has shown that an approach that is both receptive and based in the ethics of care can work with the four principles approach to find a solution.

Nonetheless, there remains a further possibility. Rather than working to principles it is possible to structure decision-making around a consideration of interests of the individuals involved. This next section will investigate whether this provides an addition avenue for a care provider to employ in dementia care.

7.3 BALANCING INTERESTS

The consideration of interests has already been encountered. In earlier chapters, the focus was primarily with the interests associated with the moral status of personhood or full moral standing. It was the concern about the implications of the potential loss of this moral status in severe dementia that has led to a move in recent chapters to find an alternative approach. However, this generates the worry that by moving the care
recipient’s moral status away from the centre of the ethical picture, it will leave open
courses of action that arguably should be forbidden. This is perhaps most keenly felt in
the debate over euthanasia where the interests of society are pitched against the
protection of the individual with dementia from being killed (Johnstone 2013; Sharp
2012). However, it can also be seen in less extreme circumstances when people need
protection from treatment that is deemed not in their (best) interests.

So this section will see if responding to people’s interests is sufficient to allay concerns
that might be brought by the loss of the moral status of personhood. An important
contribution to this discussion can be found in Peter Singer’s principle of equal
consideration of interests:

The essence of the principle of equal consideration of interest is that we give
equal weight in our moral deliberations to the like interest of all those affected
by our actions (Singer 2011: 20)

Firstly, it is worth noting that Singer (2011) doesn’t abandon the idea of personhood
altogether. For Singer, being a person adheres to a Lockean definition of the term. As
outlined in Chapter 3 (3.1) this means being a rational being who is aware of
his/her/itself as a distinct entity with a past, present and future. Having this capability
brings different interests and arguably a different moral status. So, initially it appears
that the original problem has returned. What happens to those who are not able to meet
these requirements?

A key difference is that Singer (2011:66) does not wish to ‘place a gulf’ between those
with and without these capabilities in the same way as with some of the personhood
theories discussed in earlier chapters. The point for Singer (2011) is that all entities
have different interests which must be considered equally, regardless of species or any
other attribute. Personhood merely produces a particular set of interests which can
then be balanced against the interests of other entities. Personhood is not a special or
exalted status; it merely generates a set of interests that could still be out-balanced by a
sufficiently larger number of less weighty interests.

Another key aspect of this approach is its lack of partiality, and in this way it stands
somewhat in opposition to the ethics of care approach argued for above. The ethics of
care approach tends to focus on attention to those near and/or dear to us. It therefore
rejects Singer's argument that we should equally consider the interests of a child who is about to starve in a faraway land in the same way we would if a child was about to drown in a pond in front of our eyes (Slote 2007; Singer 2011).

However, this tension between Singer’s approach and that of the ethics of care is not as stark as first appears. Slote argues that it is possible to feel empathy for those who are not near and dear and furthermore it is desirable for this to be cultivated by moral education (Slote 2007). Coming from the other direction Singer points out:

‘...it would be absurd to propose that from now on we all regard ourselves as equally responsible for the welfare of everyone in the world.’ (Singer 2011: 204)

So there may, after all, be some points of contact between an interest-based approach and the care ethics approach, despite the methodology being clearly very different.

Ultimately, Singer’s approach requires that weighing and balancing occurs in order to achieve the best outcome for all interested parties. This brings with it the same problem as principlism in that different people will assign different weights to interests and therefore balance them differently. An example of balancing interests can be found as a component of the ethical framework for dementia from the Nuffield’s Council on Bioethics (2009a)

7.4 THE NUFFIELD COUNCIL ON BIOETHICS REPORT

7.4.1 AUTONOMY AND WELL-BEING INTERESTS

The Nuffield Council on Bioethics (2009a) have produced a six component ethical framework on ethical issues in dementia care (Appendix B).

This framework is described as having "...a methodology for approaching ethical decisions; beliefs about the nature and impact of dementia; and a set of interlinked ethical values.” (Nuffield Council on Bioethics 2009a: 20).

It was previously discussed in the context of autonomous personhood. Here, it was highlighted how the Nuffield Council split the interests of the individual with dementia into two aspects: autonomy interests and well-being interests. Autonomy interests, as the name suggests, are the interests that people with dementia have in their autonomy being respected. However, Nuffield recognise that autonomy is a contested concept and
they argue that it needs to be understood in a way that is not rationalistic and allows for interdependence in relationships.

Chapter 2 (2.10) found that the Nuffield Council’s approach was in line with a relational understanding of autonomy, as they argued that a person’s sense of self should be grounded in social and family networks. As such, the Nuffield Council argues that carers’ and families’ interests also form part of autonomy interests of individuals with dementia. However, these autonomy interests, as outlined by the Nuffield Council, have a wide scope. As well as including the interests of those near and dear, weight is also given to autonomy interests by emotional responses. Yet this seems close to the definition of the other aspect of interests identified by the Nuffield Council i.e. well-being interests, as described here:

‘A person with dementia clearly has an interest in being helped to maximise their well-being, an important aspect of which involves the satisfaction of their desires and preferences’ (Nuffield Council on Bioethics 2009a: 28)

As a result it was suggested that if autonomy interests are to include emotional responses then they are likely to conflate with at least some well-being interests.

A reason given by the Nuffield Council for making the distinction is that those who believe that autonomy interests no longer apply due to cognitive decline will recognise that promoting well-being is still an important aspect. However, it is debatable whether those who believe that autonomy is based in rationality will also believe that well-being interests alone give sufficient reasons to respect what they might consider irrational preferences and desires. On the other hand, those who believe that autonomy can be based on non-rational elements such as desire do not need to consider the aspect of well-being interests that relates to this at all.

In the context of the current chapter, taking the focus away from autonomy might help to simplify the situation. As a result, the Nuffield Council’s approach might be better seen as merely balancing interests without adding the distinction of well-being or autonomy. Each interest is then assessed on its merits. For example, people with the most severe forms of dementia can feel pain and would have an interest not to feel this, even though other interests related to a higher level of cognitive function might have fallen away.
Though, there is more to Nuffield's framework than merely balancing interests. The framework also brings in the concept of personhood.

7.4.2 RECOGNISING PERSONHOOD

Component 6 of the Nuffield Council’s framework entitled ‘recognising personhood, identity and value’ states:

‘The person with dementia remains the same, equally valued, person throughout the course of their illness, regardless of the extent of the changes in their cognitive and other functions.’ (Nuffield Council on Bioethics 2009a: 21)

The Nuffield Council hopes to hold onto a personhood account in order to protect rights and entitlements, but it raises the question of what factors would lead the person with dementia to be equally valued. Unlike Singer (2011) above, it is not linked to their interest account, which would have meant that personhood itself would have brought a particular set of interests to be weighed. Instead it appears that this component needs to be seen as a separate issue to component 2 which relates to interests. It is possible therefore that a decision based on interests might conflict with any prohibitions based on the individual with dementia being a person.

The Nuffield Council offer two reasons why people with dementia are considered persons. The first draws on Jaworska’s (1999) work by stating that the capacity of people with dementia to value experiences is indicative of personhood. The second states that personhood derives from people’s emotional, spiritual experiences as fellow human beings, not merely their cognitive abilities. This second reason is distinct from the first and does not necessarily complement it. To have the capacity to value (the first reason) requires a cognitive ability. Yet, the second reason argues that personhood should not be seen exclusively in terms of cognitive abilities. Nuffield seem to be hedging their bets by drawing on as many sources as possible to maintain personhood.

Earlier chapters of this thesis found significant philosophical difficulties with these avenues, a point that appears to be recognised by the Nuffield Council (2009a: 31) when they state:

‘We do not aim to settle these controversies, but simply to offer practical and policy guidance regarding ethical issues arising in the care of people with dementia. From this perspective we believe that the position that a person
retains their identity throughout the course of dementia (even though they may behave in profoundly different ways) provides a better guide to policy and practice.’

So, the belief on which continued identity is founded remains controversial. This may well cast some doubt on the authority of the framework to guide practice and policy. Furthermore, it does not amend the conclusions made about personhood in earlier chapters.

7.4.3 CASE-BASED REASONING – CASUISTRY AND MORAL PARTICULARISM

Another dimension in the Nuffield’s Council’s framework states that decisions need also to be made in the context of ‘case based’ reasoning.

‘This methodology has three main stages: identifying and clarifying the relevant factual considerations; interpreting and applying appropriate ethical values; and comparing with other similar situations.’ (Nuffield Council on Bioethics 2009a: 21)

The first two stages in component one can easily be made consistent with an approach that balances interests. However, the third stage in the approach introduces an element of casuistry:

‘A third feature of sound moral judgments is they often involve comparison with other similar cases where it has been clear what is the right thing to do.... In other words, one difficult decision can be compared with another decision where the issue has already been decided.’ (Nuffield Council on Bioethics 2009a: 22)

Hence another factor to bring in is what has been decided before. However, as the Nuffield Council point out, these past decisions may well have to be revised in the context of each situation being individual and as such they are not suggesting casuistry in the sense that there is no need for ethical reasoning to be applied to the current situation.

This form of strong casuistry is also rejected here. To take a strong casuist view is to rely only on past decisions and to eschew the idea of reasoning which is distinctly ethical. As Arras (2013) points out, this approach converges with moral particularism (Dancy 2006) which argues that reasoning about moral matters is not distinct from ordinary reasoning in any way. In other words there is no requirement for notions such principles or virtue as a form of moral argument. This approach is rejected due to the
seemingly implausible idea that an ethical decision (e.g., I should tell the truth?) can be based merely on knowing a collection of facts. There is a need to argue why a particular action is right or wrong by employing ethical ideas (e.g., lying is disrespectful or not worthy of praise) in order to make a decision.

Nonetheless, a weaker form of moral particularism does offer a convincing argument that such a moral judgement by a virtuous agent cannot be based solely on following broad principles or rules (Ridge & McKeever 2007). This idea is in tune with some of the elements described in the ethics of care in the previous chapter. The elements here being that a decision needs to be sensitive to context and current ‘facts of the matter’ rather than merely relying on moral principles in a rigid and abstract way.

A weaker form of casuistry has been used throughout this thesis. This is where previous cases can be used to inform current judgements rather than determine them. There is an argument for a compatibility between the more flexible use of principles and a weaker form of casuistry in the sense that principles are highly unlikely to be formulated without some reference to past situations and paradigm cases are likely to have principles embedded into them (Beauchamp and Childress 2013).

Drawing on such an approach, The Nuffield Council on Bioethics (2009a: 96-111) apply their framework to a number of examples in Chapter 6 ‘Dilemmas in care’, namely the use of assistive technologies, freedom of action and risk, sexual relationships, truth-telling, restraint and abuse. In each of these it is fair to say that the balancing of interests is the key factor in the analysis.

Taking the example of the use of assistive technologies, The Nuffield Council point out how they can contribute to a person’s autonomy and well-being interests but also can work against them, depending on how they are used. A device that monitors someone’s movement is generally justified by an appeal to manage the risk to the individual being monitored. The device may be a less restrictive solution to risk management such as a locked door or more direct observation. However, the device itself may become a way of controlling the movement of the individual in a way that does not promote their interests.

There are also the interests of the care provider to consider. It could be that it is simply too much of a strain on the care provider not to seek some technological help. In a care
home situation this may be due to low staffing levels. In a someone’s own home, it may be that, for example, a daughter looking after her mother with dementia who lives in a separate part of the house needs the peace of mind of being able to see that she has not come to harm. Nonetheless the use of a camera when consent is not possible arguably is still an invasion of privacy, even when someone is unable to understand that their privacy is being invaded.

Ultimately, it is not clear how to weigh and balance the various interests of the care recipient and the care provider. Making a decision which attempts to maintain personhood, along with the need to consider previous decisions adds further complexity. As a result, the Nuffield Council’s framework may prove too complex to offer options for the care provider.

7.5 BEST INTERESTS REVISED

The Nuffield Council make frequent reference to the concept of best interests which also has an important role in the Mental Capacity Act 2005. They point out that best interests as understood in the Act takes account of both autonomy and well-being interests.

Recall that Section 4(6) of the Mental Capacity Act 2005 requires the person making the best-interest decision to consider...

‘...so far as is reasonably ascertainable—

(a) the person’s past and present wishes and feelings (and, in particular, any relevant written statement made by him when he had capacity),

(b) the beliefs and values that would be likely to influence his decision if he had capacity, and

(c) the other factors that he would be likely to consider if he were able to do so.’

Statements (a) and (b) are related to autonomy, either precedent or present. The other factors suggested by statement (c) might be considered to be based in well-being interests.

However, it is worth reiterating that best interests as understood here is not necessarily what is best for the individual in a general sense. It may be that to follow a decision that respects the person’s wishes, beliefs, values, and other factors he would consider, may
not necessarily produce the best outcome in the opinion of others. An example might be where somebody has a long standing belief about staying in their own home, even though this is now causing significant health and safety concerns. To respect the long-standing belief would arguably not adhere to Buchanan and Brock's (1990: 88) definition that acting in someone's best interests means ‘...acting so as to promote maximally the good of the individual’ as the good of the individual’s health and safety, or quality of life, may be deemed to outweigh the good of respecting his/her choice.

Best interests in the sense outlined by Buchanan and Brock is much closer to (if not synonymous with) the concept of hard paternalism. Beauchamp and Childress (2013: 218) suggest that ‘...in hard paternalism the intended beneficiary does not accept the values used to define his or her own best interests.’ Though they point out that in soft paternalism ‘...the intended beneficiary’s conception of his or her best interests...’ (p218) is reflected in the decision.

Both these understandings of best interests meet difficulties in how they might be ascertained by the care provider or decision-maker. This is particularly the case if the decision-maker is a member of a professional group who may have certain beliefs about what constitutes someone's best interests or have their own interests invested in particular outcomes (Tuckett 2006). Despite the Mental Capacity Act being a piece of legislation that seeks to promote autonomy, Williams (2014 et al: 84) found that the outcome of best interests decisions tended to focus on managing risk and '[i]t was only on rare occasions that the outcome of a best interests decision resulted in an individual achieving greater independence.'

It is difficult to resolve the tension between a legal and ethical approach. The law seeks a clear decision to be made in someone's best interest that can then be applied. Ethicists, on the other hand, may take a more flexible view of what might be meant by such a term.

Nonetheless, the idea that the 'best' outcome can be objectively determined is not alien to ethical schools of thought. Namely, consequentialism takes such an approach though it is does so in a way that looks beyond the interests of individuals.
7.6 CONSEQUENTIALISM

7.6.1 OUTLINE OF CONSEQUENTIALISM

Darwall (2003:1) sums up what makes consequentialism distinctive as an ethical approach:

‘Consequentialism begins with the idea that there are values that are prior to morality. Even if there were no moral right and wrong, some things would still be good and others bad.

...

What makes the values nonmoral ... is that they involve evaluations of outcomes or states rather than distinctively moral evaluations of agency or character.’

So, for consequentialism, the best outcome is the one that maximises desired values and minimizes undesired ones, regardless of the nature of the actions involved. As Singer points (2011: 2) actions are only assessed in terms of how they further particular goals.

‘Consequentialists start not with moral rules but with goals. They assess actions by the extent to which they further these goals.’

For example, it could be advanced that it would be better to have less coercion in the world regardless of the actions that bring this about (Parfit 1984). The goal of less coercion is a desirable one. However, in achieving that outcome, consequentialism would allow individuals to be coerced and it would be acceptable to coerce them, just as long as the end result sees a reduction in coercion in the world overall. An example might be the state using coercion to prevent a particularly coercive individual from behaving in coercive ways towards others.

As such, standard consequentialism promotes values in an agent-neutral way rather than honouring values relative to the agent (Pettit 1997; Nagel 1988; Parfit 1984). This means that outcomes are assessed as a state of affairs which people wish to promote rather than honouring a value relative to the agent in a particular situation.

This can also be illustrated in the example of being loyal to friends (eg. Darwall 2003). It is reasonable to state the premise that the world is a better place when friends are loyal to each other and they are not betrayed. However, the agent-neutral approach states there may be times when it is better to betray a friend. This is because it is possible that
the act of betraying one’s friend would make it less likely that others would do the same (perhaps due to witnessing the horror of the betrayal) and as a result there would be less friend-betraying in the world overall. Here, the value of loyalty is neither promoted relative to this agent nor honoured overall but it is promoted agent-neutrally. The fact that an individual believes it is wrong to betray his/her own friend is not relevant if the sole aim is to reduce the number of friends being betrayed overall.

The permission to betray a friend in order to increase loyalty appears a more counter-intuitive result than the coercion example as having an eye to the greater good does not seem to defend such an action. It highlights a problem in classical consequentialism that individuals can be unjustly disadvantaged in this way. Other forms of consequentialism seek to avoid this problem. Though, all consequentialist theories share the commitment to promoting one or more agent-neutral values, they can be differentiated based on whether it is the consequences of the individual act that is relevant or the consequences of certain rules being followed.

7.6.2 RULE CONSEQUENTIALISM AND CONTRACTUALISM

In rule consequentialism, the aim is to promote desirable states of affairs by the use of rules. Unlike act-consequentialism described above, these rules can be based on agent-relative concerns. Such a concern would be the one raised above that it is wrong to betray friends but also wrong to betray my friend. Rules relative to the agent are allowed just as long as these rules are able to promote states that are more valuable in an agent-neutral sense (Darwall 2003).

So, a rule consequentialist would say that having a rule that forbids betrayal of friends produces a more positive state of affairs than not having this rule. As such, it would be forbidden to betray a friend, even if, for some reason, betraying a friend would in this particular case mean that there is more loyalty produced overall.

Even though following a rule-consequentialist decision procedure will not guarantee the best consequences for each act in the way an act-consequentialist one aims to do; it is argued that better consequences will be produced in the long term by following rules rather than trying to calculate the best outcomes on a ‘case-by-case basis’. This is because people can make mistakes predicting outcomes of their acts or have skewed beliefs about the benefits being brought by their decisions (Hooker 2011; Parfit 2011).
Having a decision procedure based on rule consequentialism has the advantage of removing some of the possible errors or excessive behaviour that might be produced by attempting to act in every situation to maximise a particular value. It also seems intuitively right to prohibit people from acts such as betrayal, even if a betrayal in certain circumstances might produce a better outcome for loyalty overall. It is more acceptable to act within rules that others would generally agree promotes the greater good in such situations, even if for some reason it would actually not produce the best consequences in a particular case. The argument follows that society appears better off overall when people follow rules or principles, rather than merely focussing on outcomes.

Following this approach, Hooker proposes the following formulation for rule consequentialism:

‘...what makes an act morally permissible is that the act is permitted by the code of rules whose more or less universal acceptance would produce the best consequences, impartially considered.’ (Hooker 2014: 40)

Rule consequentialism requires that rules once accepted are followed, rather than the agent acting with an aim to promote a particular value in each instance. This formulation may also be aligned with public acceptance rule consequentialism (Sinnot-Armstrong 2014) and a similar formulation can be found in Brandt (1965).

This emphasis on public acceptance has some similarity with Scanlon’s (1998) version of contractualism which says that an act is wrong if it is allowed by a principle that a person could reasonably reject. Developing this thought, a possible convergence between a Kantian form of contractualism, rule consequentialism and a principle-based ethics has been suggested by Parfit (2011: 412-413) in his Triple Theory as outlined below.

‘An act is wrong if and only if, or just when, such acts are disallowed by some principle that is

one of the principles whose being universal laws would make things go best,

one of the only principles whose being universal laws everyone could rationally will,

and

...
a principle that no one could reasonably reject.’

So, for Parfit what is fundamental is the claim that an act is wrong only when it is disallowed by a principle that will make things go best overall and can be both willed by all and cannot be reasonably objected to. This result is significant here as it creates a conceptual link between rule consequentialism and a principlist approach discussed earlier in the chapter.

7.6.3 APPLYING RULE CONSEQUENTIALISM TO DEMENTIA CARE

Consider the following situation.

A woman with moderately advanced dementia on a dementia care unit is disturbing other people by shouting out loudly. The care providers have employed a number of strategies to try and establish what is causing the woman to shout. Some of these are successful for a short time but currently this is not effective. After a number of hours, the other people with dementia are starting to get increasingly upset by the noise. The woman making the noise is able to walk and does not wish to stay in her room. However, a number of staff would prefer to keep her in her room as this contains the noise sufficiently to prevent it from disturbing other people.

The staff who, against the wishes of the woman, would rather keep her in her room may look to justify their decision by appealing to the good that results overall. The value they hope to maximise would be the reduction in distress for the other people on the unit. This would need to be balanced with the distress caused to the woman by restricting her liberty but they may believe that this is outweighed by the reduction in distress to others affected.

Yet, this justification draws on act consequentialist reasoning that has already been criticised above. So in order to frame this decision within a rule consequentialist framework a rule such as the following could be employed:

It is only permitted to restrict somebody’s liberty to reduce the distress of others if there is a likelihood that this distress will be severe and there is no reasonable alternative.
As discussed, both Parfit (2011) and Hooker (2014) draw on the idea that rules need to aim for universal acceptance, not just within discrete societies or particular situations. Is this plausible for this rule? There may be disagreement. Restricting someone's liberty is a serious matter and the proposed principle recognises that liberty can be restricted if the likelihood of distress is severe and there is no reasonable alternative. Yet this begs the question of what makes an alternative unreasonable and how severe the potential distress has to be in order to warrant a restriction of liberty. Can this be measured? People may disagree about how much distress is needed before a restriction of liberty can be justified. The idea that people can have their liberty restricted too lightly may in itself cause distress across society, due to a fear of liberty being restricted without sufficient justification.

Assuming the principle is valid and meets the triple theory criteria outlined by Parfit, the problem remains that a value such as liberty may be incommensurable with a value such as reduction of others' distress (Sinnot-Armstrong 2014; Egglestone 2007). In short the rule may be valid but how it is applied is still open to interpretation and it is difficult (arguably impossible) to find rules clear enough not to be.

7.7 FROM RULE CONSEQUENTIALISM TOWARDS A COMBINED MODEL

The process of formulating rules for a society to follow is neither straightforward nor uncontroversial. Despite the best efforts of consequentialist reasoning, what the content of these rules should be and how they might be internalised remains unclear.

Furthermore, the intractable problem remains of what should be done when two seemingly compelling rules conflict (Egglestone 2007).

One answer is to draw on the suggestion of Brandt (1965: 228) that when there is no clear priority between two applicable but competing rules then it is necessary ‘...to take whatever course of action would leave morally well-trained people least dissatisfied.’ This is significant here as this ‘remainder-rule’ implies the idea that it is sometimes necessary to following exemplars, as well as suggesting that a feeling of satisfaction is relevant in the decision. This echoes the arguments that can be found in the discussion of virtue ethics and the ethics of care in the final chapters of this thesis.
So, drawing together the contemporary work of Slote (2013) and Parfit (2011) a formulation can be produced. The consequentialist discussion has ultimately returned back to the idea of a virtuous (or morally well-trained) individual. A good care provider will respond based on their good character and, in particular, a well-developed virtue of receptivity that seeks to identify with how the individual might be feeling and what they might prefer.

There are times when a more structured approach will be required in order to assist the care provider with their aspiration to act ethically. It is concluded here that such an approach can indeed be based on an assessment of relevant moral principles as well as the preferences and feelings of those involved.

It is further concluded that the best approach for this is the Triple Theory as described above. This is mainly due to it having a firm conceptual basis in rule consequentialism and contractualism. Beauchamp and Childress’s (2013) four principles might be expected to produce similar results. As discussed, the four principles are based on prima-facie duties, which are expected to lead indirectly to the morally right solution.

Overall, it is important to emphasise that the principles are merely there to provide a range of acceptable options for the care provider. How the options are then prioritised, and which courses of action are chosen, will depend on how values are balanced. Good character is the ultimate arbiter. Furthermore, how the chosen option is carried out, is based on receptivity in character of the care provider who will empathise with the thoughts and feelings of those affected as well as the broader context of sociopolitical context of the decision.

So, returning to the example above, it is necessary to be receptive both to the preferences and feelings brought by situation for all the parties involved. The woman concerned has a desire to move around the ward but the distress of others from her noise is also evident. The people involved feel a pressure to ‘do something’ to improve the situation and as care providers in a clinical situation they have the power to do so.

The care providers need to make a receptive decision. In order to guide this, they may well have in mind a rule consequentialist principle such as the one above that it is only permitted to restrict somebody's liberty to reduce the distress of others if there is a likelihood that this distress will be severe and there is no reasonable alternative. So,
with this principle in mind, the care providers should explore all reasonable alternatives in order to prevent the woman’s liberty being restricted. Negotiation with the woman may be possible to some extent depending on the level of cognitive impairment and the strength of the relationship between the woman and the individual care providers.

Nonetheless, whether the alternatives are reasonable is a matter of judgement. Perhaps finding an alternative larger space for the woman to make the noise is reasonable as it requires less of a restriction of liberty than being confined to a small room. On the other hand, it could be argued that the problem behaviour does not cause distress severe enough for even a more limited restriction of liberty such as this.

The care providers need to be guided by their virtue in carrying out an action that is both acceptable and will bring positive feelings to others. This would probably mean being as gentle as possible within the limits of still preventing what is perceived as unacceptable distress to others. Furthermore, there is also the broader context to consider such as finding a way that the situation can be avoided in future, perhaps by a change of environment where the woman would be able to make noise without disturbing others, or by seeking a situation where the woman is happier and no longer feels the need to shout out.

The good character of each of the care providers will be reflected in the actions they carry out and these actions will bring positive feelings to other receptive individuals observing his/her actions. In this example, it is proposed that a compassionate approach which seeks to engage on an emotional level with all concerned while following a principle of least restrictive care is most likely to elicit such a response.

7.8 CONCLUSION

This chapter marks the end of the philosophical investigation. An answer can now be proposed as to which philosophical approach provides the best foundation for the ethics of dementia care. This will be outlined in the form of an ethical model that is informed primarily by the ethics of care which is both sensitive to sociopolitical context and is connected to a virtue ethics approach grounded in the virtue of receptivity. Within this, the current chapter has found a compatible role for a decision-making framework, which is based on the contemplation of principles that adhere to Parfit’s
Triple Theory. The next chapter will outline the structure of this model and begin the work of how this model might be used as a tool for ethical leadership to improve the situation for those receiving and providing dementia care.
8 A NEW ETHICAL MODEL FOR DEMENTIA CARE AND ITS APPLICATION

8.1 INTRODUCTION

How to respond to increasing numbers of people with dementia is an urgent concern for society. Though there has been some progress in reducing dementia incidence in recent years, estimates still suggest that the numbers of people with dementia will double worldwide in a generation (Prince et al 2015; Banerjee 2013).

As discussed in this thesis, dementia presents a particular challenge in terms of formulating an ethical response for care. This is because the progress of the condition affects many of the attributes on which ethical thinking might usually be founded. Dementia also raises questions about personal identity and what it is that we value in fellow human beings.

It has been recognised elsewhere that philosophy has a central role to play in bioethics (Savulescu 2015). In line with others in the field such as Hughes (2011a), the case has been further advanced that philosophy can help people make better ethical decisions in dementia care. This thesis has examined a wide range of philosophical ideas in an effort to establish which approach provides the best foundation for the ethics of dementia care. It has also examined critically the philosophical underpinnings of pre-existing frameworks, the most prominent of which are person-centred care (Kitwood 1997), the four principles approach (Beauchamp and Childress 2013) and the ethical framework from the Nuffield Council of Bioethics (2009a). The research question has been investigated away from the constraints of professional categories, instead applying to everyone who provides care to someone with dementia.

The result of this investigation has been to establish a novel and rigorous way of understanding the ethics of dementia care drawing on these philosophical influences. In this chapter the proposed ethical model for dementia care will be outlined, along with a discussion of how it can be applied.
8.2 SUMMARY OF THE PHILOSOPHICAL APPROACHES EXAMINED

8.2.1 AUTONOMOUS PERSONHOOD

Personhood is a term closely associated with the new culture of dementia care (Kitwood 1997); however, it is variously understood. For this thesis, personhood has been understood as an evaluative term meaning that the holder has the full moral status associated with persons, which brings with it particular protections and entitlements (Jaworska 1999; Jaworska and Tannenbaum 2013).

The aim of the first section of this thesis was to establish how this moral status might be grounded for people with dementia in order assess the viability of an ethical model developed with personhood as its central element. It was initially investigated whether autonomy in the care receiver is sufficient to ground the moral status of personhood. If successful then an ethics based on the autonomous personhood (Christman 2015) of the receiver of dementia care would have been possible.

Autonomy is considered by some scholars to have been a dominant force in recent legal and ethical thinking in the Western World (Foster 2009). This is also reflected in the area of dementia care. It can be seen in legislation, such as the Mental Capacity Act 2005 and in the emphasis in policy on the promotion of independence and individualism in the area (Nolan et al 2004).

Analysis of the concept revealed that in order for autonomy, understood in a standard way, to ground personhood, it must include the ability to reflect on immediate preferences in terms of one’s values for life as whole. This is because choices made without such reflection are too open to challenge to carry the necessary moral weigh. It was argued that the necessary level of reflection is unlikely to be possible for people with more advanced forms of dementia, and, as such, autonomy understood in a standard way would not suffice to ground personhood for individuals in this situation.

So other avenues were explored to investigate how autonomy could be modified in order that it might ground personhood for people with more advanced dementia. A commonly proposed solution is to use precedent autonomy (Dworkin 1986), where an autonomous choice of an individual from the past remains applicable when the individual is no longer considered capable of exercising autonomy. This is the
philosophical concept which underpins various types of advance directives, such as advance decisions used in the Mental Capacity Act 2005.

It was argued that precedent autonomy requires a social view of autonomy linked to a narrative personal identity in order for it to do the work of maintaining autonomous personhood. This is because there is not a sufficient psychological connection between a past and present self in order to maintain personal identity in the usual way.

However, this social view brings philosophical problems due to the risk that the beliefs and interests of the social group around the individual will overwhelm the individual self and the person’s narrative rather than maintaining autonomy in a genuine way. In addition, there remain practical problems of accurately applying someone’s past wishes to a present situation. All this leads to the risk that the current individual will be subject to treatment that is not from the surviving autonomous will of the current individual to whom it being applied. It is concluded that the controversy over the moral authority of advance directives remains unresolved.

Though, it is not concluded that autonomy is therefore irrelevant. For many with dementia, it is valid concern and respecting preferences, whether fully autonomous or not can form a prima facie principle in ethical decision making. The argument here is that autonomy needs to be put in context as an important but not a central all-encompassing value for dementia care.

8.2.2 PERSONHOOD MORE BROADLY UNDERSTOOD

The discussion moves on to consider how personhood might be understood in a way that is not reliant on autonomy. It was hoped that this might provide a more inclusive route to the moral status of personhood.

Following an exploration of various academic views on personhood it is suggested that it is possible to have a form of personhood based on self-conscious valuing (Harris 1985) for all except those with the most severe dementia; the criteria being less stringent than the requirements for autonomous personhood. However, the presence of self-consciousness is more doubtful for people with severe dementia, due to a further reduction in psychological capacities. There is some evidence that a basic sense of identity based on a simpler form of consciousness continues into severe dementia.
Yet, if personhood is founded on simpler forms of consciousness then this approach produces a demanding moral vision. This is because, in order to be consistent with a purely psychological view, it must extend prima-facie protections and entitlements to non-human animals with similar psychological abilities.

A reasonable response is to imagine personhood as something that can be a matter of degree rather than all or nothing (DeGrazia 2008). Linking this to the notion of prima facie duties, it can then be proposed that people with different levels of personhood will incur different prima facie duties from a care provider. Yet there are practical difficulties with trying to assign entitlements/protections/duties to those with ‘lesser’ forms of personhood. It becomes a line drawing exercise that is liable to disagreement and controversy.

Therefore, as with autonomy, there’s an apparent need to explore views modified to be inclusive of dementia. Kitwood’s (1997) view of personhood is undoubtedly the most influential, and has had a profound effect on dementia care. Hughes’s Situated Embodied Agency view (2001; 2011) also presents a view of personhood for dementia that is both plausible and positive for people with more severe dementia. However, each view has philosophical difficulties in terms of how they define personhood.

Kitwood’s view of personhood relies on others bestowing the status on the individual with dementia. This may work within the context of a positive environment where people are willing to bestow personhood in this way. However, this may not be case in all situations. If those caring for people with dementia do not wish to bestow personhood on them, there is no argument in Kitwood that obligates them to do so in terms of moral status. Hughes’ view aims to overcome the flaws in this and other social constructivist positions of personhood. However, the position generated is not an argument for moral status. It is, instead, a phenomenological position, which ultimately reflects a more promising approach for an ethical model to take.

8.2.3 DIGNITY, EXISTENTIAL AND SPIRITUAL VIEWS

Due to the practical and philosophical difficulty basing an ethical model on autonomous personhood and personhood more broadly understood, the idea that it might be grounded on a dignity of humanity (not necessarily tied to these concepts) was explored.
It was suggested that in common use the term ‘person’ might mean something different to the standard philosophical use of the term, and that dignity may be the key to this. Yet, when analysed as a theoretical concept, dignity was hard to delineate. It was not possible to fully differentiate subjective forms of dignity from autonomy. Objective forms of dignity which aim to delineate the concept independently of someone’s subjective experience (Gallagher 2004) were found to be more promising. However, they remained culturally relative, in that an objective view of what dignity is for a human being is sensitive to cultural values.

Nonetheless, dignity is a powerful notion in care, which for many who use the term is based on an intuitive understanding of how fellow human beings ought to be treated. This line of argument on the substance of such intuitions led to an exploration of existential views and the importance of the body. This is again in tune with the views expressed by J.C. Hughes (2013: 356) who states that judgement in dementia care is ‘...based on feelings akin to an aesthetic sense of what is right.’

This begins a shift in philosophical approach. Care providers need to use their ability to feel, making aesthetic judgements rather than merely drawing on their ability to make reasoned judgements from facts presented. Decisions are not made solely in terms of obligations generated by the situation and attributes of the human being who is cared for. Emotions brought by factors such as empathy for the vulnerability of the other can generate a positive ethical response in the care provider, rather than that vulnerability being perceived in the context of a loss of capabilities. As such, the end of the chapter marks the beginning of the move away from a focus on moral status of the care recipient towards the experience and inner life of care providers, both emotionally and psychologically in the caring relationship.

8.2.4 VULNERABILITY AND VIRTUE

Virtue ethics looks to the development of character as the central concern in the moral life. This chapter further developed the argument that there is an opportunity to cultivate good moral character in care providers through an understanding of the vulnerabilities that we all share in some degree as human beings. This is also guided by moral education and by emulating other virtuous characters in life and literature. In line
with Sellman (2011) it was argued that our teachers are all around us and that we can cultivate virtue in various ways.

A number of virtues were considered relevant for dementia care providers such as trustworthiness, compassion and courage. It became clear that these and other virtues may conflict. In order to try and solve this problem, classical Aristotelian virtue ethics relies heavily on the more intellectual notion of practical wisdom and aims for human perfection though the doctrine of the mean and the unity of the virtues. Yet, ultimately, Aristotelian virtue ethics was not found compelling due to this emphasis on intellectual prowess.

Instead, it was argued that the virtue of receptivity proposed by Slote (2015; 2013) should be the central virtue for dementia care. This virtue aims to develop empathy in order to identify with the experience of others and respond in a way that reflects this. This is part of a move by Slote to rethink both rationalistic Enlightenment values and the perfectionist tendencies found in Aristotelian virtue ethics. As such, an essential part of developing receptivity is to recognise and accept the limitations of ourselves and those around us. Slote argues that receptivity moves us beyond a reliance on rationality to value also the non-rationality in human life.

It follows that exemplars of receptivity will not be aiming for perfection, even in receptivity itself, as they know that is an unobtainable aim and will in fact distance themselves from those they hope to inspire. Moral education from the perspective of receptivity is more of an empathic and emotional process than an intellectual one. Overall, the argument of this chapter concurs with Slote (2015; 2013) when he states that a combination of rationality and empathy are necessary for us to have a full appreciation of the good life in virtue ethical terms.

8.2.5 THE ETHICS OF CARE, EMOTION AND THE ROLE OF SOCIOPOLITICAL JUSTICE

The ethics of care brings a number of elements to the ethical model that is now beginning to take shape. It values emotions and it is therefore in line with the strategy of aspiring to a virtue of receptivity.

Through the work of theorists such as Tronto (1993) and Kittay (1999), the ethics of care also brings a sociopolitical context to the ethical decisions being made. This raises
the idea that care providers need to be supported to care and caring as a whole is something that needs to be valued by society at large. This is also reflected in the way that contextual factors, which might be considered irrelevant by more reductionist ways of ethical thinking, are seen as an essential part of finding the best way forward in the ethics of care. As such, it is also more likely to seek compromise rather than sticking to polarised positions. Examples in the main body of the thesis have shown how this strategy fits well with ethical decision making in dementia care.

8.2.6 BALANCING PRINCIPLES AND INTERESTS

A case has been made for both an ethics of care and virtue ethics playing a key role in the ethics of dementia care. Nonetheless, taking an approach that relies solely on the character of the care provider to produce ethical care is open to criticism.

The ethics of care suggests that care providers need to feel their way through complex situations in order to respond appropriately. However, in order to respond to the competing ethical demands brought by multifaceted situations, a decision-making framework may be needed to offer guidance to the care provider who is trying to act in a caring and receptive manner. As such, a more structured and rationalistic approach offers broadly acceptable options to inform the judgement of the care provider.

The aim of this chapter was therefore to consider the merits of a framework which seeks to establish and balance principles and interests, and whether this can be compatible with the approach argued for above. On examination it was found that principlist approaches such as the framework of Beauchamp and Childress (2013) can indeed be made compatible with both a virtue ethics and ethics of care approach. The role of virtue comes to the fore in terms of how the principles are balanced.

Ultimately it was argued that that it is best to base the principles on the Triple Theory of Parfit (2011), which incorporates elements of consequentialism and contractualism. This somewhat surprising result means that principles should be formulated both in terms a consequentialist measure of what would make things go best, but also they must be universally willable and be principles that nobody can reasonably reject. Actions are wrong if they are disallowed by such principles.
The purpose of the principles is therefore to present broadly acceptable option/s to the care provider. How the options are prioritised and which courses of action are chosen will depend on how the values within the principles are balanced. This judgement is based on character of the care provider and it is argued that receptivity will assist with this judgement as it will enable the care provider to empathise with the thoughts and feelings of those affected, as well as the broader sociopolitical context in making the decision.

8.3 THE ETHICAL MODEL

So the final model is pluralistic in terms of drawing together a number of philosophical influences:

**Figure 4** – A new ethical model for dementia care

There are three main elements: sociopolitical justice and mutuality; principles and the emulation of exemplars of receptivity.

Based in the ethics of care perspective, **sociopolitical justice and mutuality** provides support for other aspects of the ethical model. For the ethical situation being considered, it asks questions such as: What is the context of the relationship between the care provider and recipient? How might the political or social situation be changed to alleviate difficult ethical situations? Which courses of action might allow for both care
providers and recipients to feel fairly treated and cared for? Is negotiation possible? Can a compromise be reached?

The mutuality and sociopolitical context base of the model reflects the position that care is not merely a private concern between individuals or within families. Caring is an essential part of society and needs to be valued as such, with those carrying it out being supported in order that everyone can survive and thrive (Kittay 1999; Tronto 1993). This context is relevant at a macro level in terms of overall political and policy decision making, but also at the level of organisations or individuals. The latter is more likely to be within the sphere of influence of the individual care provider.

As discussed above, each ethical decision needs to be made based on a broader understanding of this sociopolitical context. The ethics of care approach also seeks wider information about those concerned rather than merely taking a reductionist approach. This is shown on the model by the context feeding into the judgement made by the care provider/s.

Decisions (ideally) should be made in a way that leaves both the care provider and recipient feeling fairly treated and cared for. This should involve negotiation (Brannelly 2006) and if an impasse is reached, a compromise may be needed. This element is also represented graphically in the model.

The model shows how acceptable options are presented to the care provider/s by utilising principles in order for their judgement to be employed and a caring response made. As discussed, it is proposed here that Parfit’s (2011) Triple Theory produces a stronger conceptual foundation for principles than other approaches.

Based in the virtue ethics perspective of Slote (2013), the model puts the virtue of receptivity as the central virtue for the care provider to cultivate. This perspective seeks to understand the world of the individual who is receiving care, both in terms of what they are feeling and also their thoughts and preferences.

As the model also shows, the option/s presented by the Triple Theory principles combine with the approval from exemplars of receptivity in order for a sound judgement based in receptivity to be made. In virtue ethics, some emotions are more praiseworthy than others depending on the situation. It is the most praiseworthy
intentions and their associated actions which will gain the approval of virtuous exemplars.

In practice it is envisioned that this component will often be as a result of the care provider *imagine* what a particular exemplar might do in a particular situation. This may be produced by the care provider asking questions such as:

What would my chosen exemplar think and do in such a situation?

Or perhaps by asking more generic questions, such as:

What would a good care provider think and do in such a situation?

If I am to be the good provider that I aspire to be then what do I need to think and do?

Another factor to consider is the *agency* of the individual with dementia themselves and this is represented on the model by an arrow directly linking the care recipient with the response. The model already reflects that negotiation and compromise may well be necessary. As has been discussed in earlier chapters, the amount that the individual with dementia can contribute to the response will vary depending on the level of cognitive impairment brought by the condition.

It is useful at this point to refer back figure 3 outlined in Chapter 2 (2.7). Here a flow chart was devised to show what needs to be in place either for an individual to exercise autonomy themselves or to be helped to do so. If the individual is free, willing and able to act with autonomy then the care provider has little or no role at all. Arguably this is no longer an act of care if the action has been carried out completely independently, and as such may well fall outside the scope of this thesis.

However, it is also possible that although the autonomous choice has been made by the care receiver, at least some assistance is required by a care provider in order to facilitate the act. If the individual with dementia retains autonomous personhood, then principles, such as those generated by the Triple Theory, are likely to protect him/her from a response that is paternalistic from the care provider. The model is extended to show how someone with dementia who has autonomous personhood can make better ethical decisions. As represented by the *dotted lines* this would also involve virtuous
exemplars and working within principles. This recognises that a person with dementia may well retain moral agency while requiring some care, and it follows that the care receiver (and other affected parties) can benefit in the active application of the ethical model.

8.4 APPLICATION USING A SIMPLER VERSION OF THE ETHICAL MODEL

The ethical model needs to be useable for a wide range of care providers, not just professionals or those with an academic interest in moral philosophy. For this reason a second version of the ethical model has been formulated, which uses more ordinary language and is set out in a more user-friendly way.

**Figure 5** How ethical decisions can be made in dementia care

The key elements remain the same and can be mapped onto the academic model outlined in Figure 4 above:

**Attempt to find a solution through negotiation.** This reflects the ethical idea argued for in the feminist ethics of care tradition that negotiation, and perhaps compromise, is something that may be sought if it offers a practical way of solving an ethical challenging situation (Brannelly 2006).

**Build a society that supports care providers to care.** It may not be directly within the sphere of influence of the care provider to change the political situation. However,
awareness of this idea is important as it allows the care provider to put care into context as a concern for society not merely a private arrangement between individuals.

**Consider the effect of the setting, power and relationships on the decision.** As Tronto (1993:155) suggests, resolving problems with care requires a ‘more equal access to power’. The setting for care also affects the care produced. For example, in an institution such as a hospital or care home there will be certain policy or legal considerations that need to be taken into account. At the micro level, relationships may or may not be positive for the care receiver, in terms of generating a sensitive (and receptive) care response.

**What is acceptable based on a principle such as the Golden Rule?** The adaption of this part of the model reflects the fact that not everyone who makes decisions as a care provider will be able to (or wish to) draw on Parfit’s Triple Theory for guidance. Beauchamp and Childress’s (2013) four principles approach may act a useful framework for producing acceptable options. However, in order to be as inclusive as possible this simpler model assumes only that people consider the most basic principle of morality, the Golden Rule.

In its most basic form, The Golden Rule can be formulated as

> Treat others as we would want others to treat us.

Philosophically a number of objections might be levelled at this basic form, mainly due to its ambiguity which could lead might lead to partial judgements. Some of these can be resolved by the following formulation:

> ‘We ought to treat everyone [including how we treat ourselves] as we would rationally be willing to be treated if we were going to be in all of these people’s positions, and would be relevantly like them.’ (Parfit 2011: 327)

Nonetheless, it may not be necessary to add this complication. As Parfit (2011: 330) points out, despite objections that might be levelled:

> ‘. . this [Golden] rule may provide what is psychologically the most effective way of making us more impartial, and morally motivating us.’

The key point here is that such a principle signposts acceptable options. It is unlikely to offer definitive answers. For example, we could ask ourselves whether we would want
to be lied to and many of us would say no; however, some of us might also say that we would want to be protected from the truth if it causes us severe distress. As a result, we need to decide, and an empathic response can be enhanced by emulating other empathic persons we admire as good care providers.

**What would an empathic person I admire do?** This question aims to elicit the emulation of exemplars using more ordinary language. Ideally, the person admired will demonstrate receptivity as a virtue, as well as having high levels of empathy.

**What do I think and feel is best?** This reflects the central role of both feelings and preferences as used in the academic model above.

**What do the care receiver/s think and feel is best?** As with the academic model the thoughts and preferences of care receivers are central to producing a receptive (or in less academic language) a sensitive care response. As has been discussed in depth in this thesis, the cognitive element may become less prominent as dementia becomes more severe. Nonetheless, it is still possible to be receptive to preferences and feelings. All of this culminates in the aim to care in a way that is both principled and **sensitive to the care receiver's perspective**.

As with the academic model, some lines are dotted signifying how someone with dementia, who is still able to exercise moral agency, would fit into the model. As before, the person with dementia would need to draw on the same factors as their care providers in order for their actions to be an *ethical* response to the problem relating to their own care.

### 8.5 Concrete Examples of Application of the Ethical Model

Chapter 1 outlined a range of everyday ethical issues that have been highlighted in the literature. A number of these have been discussed in the thesis. In order to aid further understanding, the ethical model can now be applied to some further examples.

#### 8.5.1 Electronic Surveillance

Care providers may use electronic surveillance measures such as tagging, tracking devices and cameras in order to manage risk while promoting benefits for both the care receiver and those providing care. Niemeijer *et al* (2010) carried out a systematic
literature of surveillance technologies in residential care. They found that the use of such technologies to manage risk and reduce care provider burden needs to be balanced with concerns that the care receiver might have about being monitored or watched. Privacy, stigma and the risk of losing human contact have also been raised as issues of serious concern to care receivers (Nuffield Council on Bioethics 2009a; 2009b; Niemeijer et al 2015; Welsh et al 2003)

Justifications can be applied on both sides of the argument. For example, a device that enables someone to safely go out could be viewed as something which promotes liberty in the sense that it allows that individual a greater freedom to move safely. On the other hand, the fact that a device such as a tag has to be worn can be seen as stigmatising and restrictive of freedom, even when the non-technological alternative involves care providers using more physically restrictive interventions to maintain safety (Niemeijer et al 2015).

Consider the example of Joe. He has moderately advanced dementia which leads to him putting himself at risk in the home environment. Joe lives in a small flat attached to the main house where his daughter and main care provider, Nerys, resides. Nerys is worried about Joe’s safety in his flat. She is concerned he might fall or otherwise injure himself. She is also worried that he is throwing food away as he seems to losing weight despite apparently eating the meals that she provides him.

As Nerys does not wish to spend all of her time in her father’s flat she decides the best thing is to set up a small camera that observes Joe in his main living area. Nerys can then get on with things in her own part of the house while observing that he is OK. Though Nerys explained to her father about the camera he seems unable to understand its purpose. Since installing the camera, Nerys has had peace of mind and has been able to get to the bottom of the food mystery, noticing that Joe has been feeding his dinner to his pet dog. However, Nerys is unsure whether she should carry on using the camera.

Firstly, Nerys would be wise to reflect on the context in which she is making the decision. As the main care provider, the relationship that Nerys has with her father is relevant. Has it been a close and trusting one? How has it changed by the progress of his
dementia? Nerys may wish to consider the feelings and beliefs she has about looking after her father and reciprocally how her father might experience being cared for by her. For example, does Nerys feel obligated to care for her father, perhaps believing it to be part of a daughter's role? She may also wish to consider if she is adequately supported and if there is anyone else she can discuss the situation with.

Nerys is unsure whether to carry on using the camera. She considers a principle of whether it is acceptable to be watched without one's knowledge. Nerys concludes that if her father had the mental capacity to understand then that would definitely not be an acceptable option due to a lack of privacy, and privacy being something that persons need to make life go best. However, due to her father's lack of understanding, Nerys is uncertain whether such a principle would apply. Nerys also believes that a principle of doing the best for her father and protecting him from harm needs to be considered. For Nerys, to not keep a close eye on her father goes against such a principle and means that she would neglecting what she perceives as her duty as a daughter.

Nonetheless, Nerys reflects on what it might feel like for her father to be watched in this way. Putting herself in his position, Nerys feels uneasy about this. She decides to talk with him again about the situation. He continues to not understand what the camera is, referring to it only as "...that black shiny button on the wall". However, he also states that he likes to keep himself to himself, a value that his daughter knows he has held for many years.

Nerys decides to respond to her uneasy feelings and remove the camera. However, she still feels a responsibility to consider how her father might be kept safe. Reflecting on her belief about being a dutiful daughter, Nerys considers whether this belief may have its origins in society placing an unreasonable expectation on her as a daughter. Nerys decides to seek support. She asks her brother if he can spend more time at the house to help her have a break and both he and Joe agree to this. Furthermore, she finds some other adaptations that would alert her if her father were to fall, without directly watching him or monitoring his movements. Finally, Nerys also decides to eat dinner with her father more regularly. Though this is not possible every day, Joe appears to enjoy this time and he starts to put on some weight.
Giving medication covertly to older adults who are unable to consent to medical treatment is not an unusual event in nursing and care homes (Haw and Stubbs 2010). In England this can only be done after a best interests meeting has been held (National Institute for Clinical Excellence 2015). In order to establish best interests, English law requires the person's present and past wishes be taken into account as well as any beliefs and values held and any other factors the person themselves would be likely to consider if they were making the decision (Department for Constitutional Affairs 2007).

As discussed in Chapter 7 (7.5), this best interests standard does not merely look at what is going to produce the best outcome for the individual objectively but also introduces an element of substituted judgement by considering what the person themselves might have decided. However, some pressure can be put on the idea that the past preferences of the individual remain valid, if there is a lack of psychological continuity for the individual concerned between this past time and the current situation.

Consider the example of Laura, who lives in a care home and has advanced dementia and diabetes. Laura requires a number of medications for her physical and mental health. These include medication to manage her diabetes and a small dose of an anti-psychotic medication which appears to reduce her mental distress. When offered medication in tablet form Laura spits these out. When asked about this, Laura does not communicate any reasons for refusal and it appears that she is unable to understand what the tablets are for. As such, she is assessed to currently lack the mental capacity to make this decision.

A best interests meeting is held. This includes members of Laura's immediate family as well as senior health and care staff who are managing Laura's care. Laura's family state that she would want to be treated as she always had strong views about the sanctity of life which they now wish to honour for her. As such the consensus from the meeting is that it is acceptable to give Laura her medications covertly as without these her diabetes would deteriorate, putting her life at risk. It is also decided that it is not in Laura's best interests to be living with severe mental distress so to carry on giving anti-psychotic medication. This
is despite the knowledge that anti-psychotic medications can have serious adverse side effects for people with dementia (Banerjee 2009).

As a result of the meeting, the care providers have been instructed to hide the medication in a small piece of cake and not to say that there is any medication there in order that Laura will take it. However, Jane who is on duty today, feels uncomfortable about this. Firstly, because it involves deception. Secondly, she is concerned about giving anti-psychotic medication, which may make have other adverse effects, when it cannot be ascertained that this is what Laura wishes.

How might the ethical model help Jane in this situation?

Firstly, Jane needs to be aware of the sociopolitical context in which the decision to give covert medication has been made. There is nothing that immediately can be done about the legal and policy situation. Though Jane may wish to lobby for a change in this, if she is uncomfortable with how the decision has been made. Furthermore, it is not immediately practical to have the prescription for the anti-psychotic drug reviewed and there is a reality that Jane may not be powerful enough to effectively challenge this decision. Though, it is hoped that adoption of this model would result in a more flattened hierarchy and a greater opportunity for all those involved in Laura’s care to negotiate a response to their situation.

Jane finds herself in a situation where she has to decide what to do about giving the covert medication. She needs to be mindful of how she feels about the situation. Laura appears happy to have a piece of cake to eat, not knowing that it contains the medication but Jane feels uneasy about the deception. She is receptive to the fact that Laura has recently been reluctant to take medication and perhaps this suggests a current preference that cannot be fully expressed.

Needing some further guidance the care provider looks to the Triple Theory principles. A principle can be formulated that it is a prima-facie wrong to lie to people as deception is not universally willable, nor is it an action that makes things go best in society. Yet, it is also the case that a principle of absolute honesty would not make things go best in society (though it is universally willable) and as such this would also fail the test set by the Triple Theory. As such, an exception needs to be built into the principle and Jane decides that it would probably be acceptable for someone to be deceived if they are
unaware of the threat to their health and there was no other reasonable option for removing this threat to their health. Jane also reasons that uncertainty over Laura’s current wishes requires that people err on the side of caution and treat her for this life threatening condition. As such giving the medication presents itself as an acceptable option.

Jane also reflects on whether it is acceptable to be giving medication that may have serious adverse effects. This involves considering whether it provides the greatest benefit for Laura in line with a principle of beneficence (Beauchamp and Childress, 2013). However, there is also a concern that a serious harm may result, even early death. The care provider considers a principle that allows a treatment which benefits but also seriously harms. She forms the view that in certain circumstances this action might be what makes things go best but could also be reasonably objected to by someone who does not wish to be harmed. Again, it is difficult to know if Laura would want to take this risk.

Bearing this in mind, Jane then considers what someone who exemplifies receptivity might do in this situation. Jane imagines that such an individual would also be uneasy about using deception as well as having serious concerns about any aspects of the medication that risk harm to the individual long term. Nonetheless, when faced with the immediate risk of deterioration of someone’s mental health Jane imagines that they would go ahead and give the medication covertly. To do otherwise could be considered irresponsible and might jeopardise trust that others hold in care providers to give medication as prescribed. However, Jane imagines that her exemplar would also have the courage to challenge any aspects of the prescription that they believed were not right. In this case, Jane’s primary concern being the possible side effects of taking the anti-psychotic medication. So Jane plans to raise her concerns with the prescriber.

Finally, the way that the response is carried out is important. The care provider is aware that openness may prevent Laura from accepting the cake. So she cannot be open about this. However, Laura ensures that the cake chosen to conceal the medication is one of Laura’s favourites and she makes her drink which shows a preference for also. The care provider also uses the opportunity to sit with Laura and the care provider is receptive to the fact that Laura appreciates this.
As Mahieu and Gastmans (2012) point out, the sexual activity of people with dementia can present challenges to the care provider. The principle concern is that people with dementia may be at risk of being sexually exploited or abused due to their reduced ability to make decisions. On the other hand, people with dementia have the human need for love and intimacy the same as other human beings and any tendency to infantilise people with dementia needs to be avoided. Makimoto et al (2015) reviewing international studies on the topic and found that sexual experiences are common but vary a great deal in their nature and degree. Furthermore, the responses to these experiences are often inconsistent and are highly sensitive to the attitudes of the care providers to the expression of sexuality in general.

In trying to make a decision in ethical dilemmas involving a sexual element, the concepts of informed consent, selfhood and personal identity are commonly drawn on within the context of a principle of autonomy and other principles such as beneficence having less emphasis (Mahieu & Gastmans 2012). This might include a form of advance directives to assist with decision-making about sexual matters. However, as discussed above, ways of maintaining autonomy and personhood through advancing dementia are open to philosophical dispute and this limits the scope of their usefulness.

Consider the following example. Ian and Angela live in a care home. Both Ian and Angela have dementia but Angela’s is considered to be more advanced. For a number of months Ian and Angela have been seen holding hands and appeared to be enjoying each other’s company. Recently, though, Ian has started spending time in Angela’s room, occasionally staying in it overnight.

Some concern has been expressed by Angela’s relatives that she may be being exploited by Ian. Furthermore, Ian is still married, though his wife is not able to live with Ian in the care home. Ian states that he misses the intimacy he used to be able to experience with his wife. Ian’s wife is sympathetic to this but is not comfortable with Ian spending the night with Angela, saying that this ‘probably crosses a line’ for her. Angela when asked how she feels about spending time with Ian states that he is a nice man. Angela appears relaxed in Ian’s company when in public areas.
The care providers have a meeting to discuss what to do. How might the ethical model help in this situation?

The context of the care home means that there are a number of people involved in making a decision about how to proceed. Ian and Angela both have dementia and this may affect their ability to make a decision in this situation. Legal aspects and local policies such as safeguarding procedures will be relevant. There is also the broader sociopolitical context of woman being more at risk of abuse from men and women’s oppression in society.

The care providers recognise an ethical principle that consent must be given for significant physical contact. This is a basic principle which is necessary for a good society and it is one to which nobody can reasonable reject. In line with (Mathieu and Gastmans 2012) they also decide that both Ian and Angela need to be aware of the benefits and risks of having a sexual relationship. However, it is difficult to ascertain whether Angela (in particular) is giving consent to this. She states that Ian is a nice man and does not appear to be uncomfortable when he is with her. However, it is difficult to know how things are behind closed doors and Angela is unable to express her views on having an intimate sexual relationship with Ian.

The care providers want Ian and Angela to be happy. In the past when Ian has been away from the home, Angela has appeared sad and states that she misses Ian. Ian has expressed similar feelings when Angela has been away. The care providers are receptive to this and want to act in a compassionate way. However, they are also worried about Angela, sensing that she is being dominated in this relationship. The care providers must also be mindful of their own views about sexuality and consider whether these views may be unreasonably prejudicing their judgement in regards to Ian and Angela’s situation.

The thoughts and feelings of Angela’s relatives also need to be taken into account. Though the care providers need to put Ian and Angela first, the view of relatives may offer some insight. Angela’s relatives express a concern that this she is being dominated by Ian. Ian’s wife, on the other hand, appears to have a sympathetic attitude merely wishing him to be happy; though, she does express some apprehension about Ian spending the night with Angela. She states that this “crosses a line”.

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The principle that someone should be able to consent to physical intimacy guides the care providers to agree that Ian and Angela should not be allowed to see each other in private in their rooms. This is a difficult decision and is against the principle that Ian and Angela should have the liberty to pursue an intimate relationship in private. Nonetheless, the general sense that Angela may be being exploited leads the care providers to take a more cautious approach. Ian is particularly upset with this decision. However, the care providers make every effort possible for Ian and Angela to spend time together during the day in public areas of the home.

8.5.4 REFLECTION ON THE EXAMPLES

The examples each draw on the three elements of the model, sociopolitical justice, use of the principles and emulation of exemplars. They seek to demonstrate how the ethical model is flexible enough to apply in complex and diverse situations by drawing more or less on the each of the elements necessary to make a decision.

The first example draws more heavily on the sociopolitical element of the model to assist the care provider, Nerys, to reflect on how she might be best supported to care for father Joe. However, a reflection on principles is central in Nerys’s decision to take the camera down.

The second example of Laura being given covert medication also relies on an assessment of principles to try and guide Jane in her decision. However, in this example, virtue is needed to act in a way that is both compassionate and measured but also courageous in order to challenge the decision that has been made. The power structure is important here, drawing again on the political aspect of the ethics of care.

Finally, the difficult decision faces the care providers who are seeking to do the right thing for Ian and Angela. Once again principles are required to help guide the decision. However, the care providers need a mindful approach here to act in a way that reflects their intuitive discomfort with the situation but is also receptive to the feelings of both Ian and Angela.

In order for care providers to develop the necessary skills and attributes to be able to best apply the ethical model in either version, the following ethical education programme is proposed.
8.6 OUTLINE OF AN ETHICAL EDUCATION PROGRAMME

The following outlines how an ethical education programme might be used to implement the ethical model. This could be carried out as a standalone course or as part of a broader programme in dementia care. It is envisaged that the courses could be run in venues such as higher education establishments, care homes or carer support groups. Overall, the objective is to make the programme as widely available and as inclusive as possible to reach the largest number of care providers.

Overall, the programme has four proposed components:

- Component one – Receptivity
- Component two – Care in a supportive sociopolitical context
- Component three – Using ethical principles
- Component four – Making ethical decisions

8.6.1 RECEPTIVITY

This is a central notion for providing ethical dementia care using the ethical model. As discussed in Chapter 5 (5.5), the first stage in cultivating receptivity as a virtue is to engage with emotions.

In order to assist people with engaging with emotions the following questions may be helpful:

- Consider your beliefs about emotion in dementia care?
- Are you fully connected with your emotions when caring for someone with dementia?
- Are there certain rules around the expression of emotions at work / in your home?

This focus on emotions can be aligned to the *Feelings Matter Most* approach to dementia care pioneered by Sheard (2009). Sheard’s work does not aim to be an ethical model nor does it name the cultivation of receptivity as a goal. Nonetheless his work is highly relevant for this first stage which aims to engage care providers’ emotions in the ethical decision-making.
In his aim to develop person-centred care (broadly understood), Sheard argues that there are a number of ‘old rules’ relating to care providers’ emotions in dementia care that need to be replaced with new beliefs.

**Figure 6:** Old rules and new beliefs for dementia care from Sheard (2009:69-89)

<table>
<thead>
<tr>
<th>Old rules</th>
<th>New belief</th>
</tr>
</thead>
<tbody>
<tr>
<td>Express emotions at work is unprofessional</td>
<td>Expressing emotions at work is needed to be an attached professional</td>
</tr>
<tr>
<td>Leaving our personal lives at home is healthy</td>
<td>Being a whole person at work is healthy</td>
</tr>
<tr>
<td>Wearing a professional mask is protective</td>
<td>Removing your mask at work and being authentic is essential in being person centred.</td>
</tr>
<tr>
<td>Carrying out the role of a manager means not being real at work</td>
<td>Being person centred leader requires the joining up of the personal and professional</td>
</tr>
<tr>
<td>Promoting restrictive rules on emotions at work is effective</td>
<td>Replacing rules at work with positive beliefs is the way forward</td>
</tr>
<tr>
<td>Being professional with families requires a ‘façade’</td>
<td>Being person centred with families involves facing jointly real emotional dilemma and placing the person living with a dementia centre stage</td>
</tr>
<tr>
<td>Turning emotions into logic is more valid</td>
<td>Turning care work back to focus on the central importance of emotions in everyone is the beginning of being person centred</td>
</tr>
<tr>
<td>Disguising emotions is a strength in staff</td>
<td>Disguising emotions at work belongs with institutionalised care. Expressing emotions at work is about your right to be a whole person at work.</td>
</tr>
<tr>
<td>Focussing only on positive emotions at work is productive</td>
<td>A new culture of opening up emotions at work has to be inclusive and also provide</td>
</tr>
</tbody>
</table>
Displaying emotions at work is a burden to others

| Displaying emotions at work is a burden to others | Displaying and sharing emotions at work with colleagues is essential. Sharing emotions within person centred staff team can unburden the weight of these feelings. |

The essence of this list is about connecting and valuing our emotions and putting these on at least an equal footing with reasoning when it comes to making decisions in a caring context. It highlights the way that emotions have tended to be seen as unhelpful and unprofessional in dementia care. These new ‘rules’ aim to radically change the situation by creating a new culture which opens up emotions.

Sheard’s approach is primarily aimed at those providing dementia care within a care home environment. As such it is not an exact fit for the aim of this thesis to apply to anyone who is proving dementia care, professionally or not. Furthermore, it is possible to be critical of the statements made here. For example, it is unclear what might ground a ‘right’ to be a whole person or what being a ‘whole person’ actually means. In a similar vein, this thesis would take issue with describing such an approach as person-centred if this means that personhood as a moral status is the most important consideration.

Yet, to make such criticisms may well be missing the broader point that is being made by these statements about the central role that emotion needs to play in dementia care. Further support for this approach, can be found in research from McPherson et al (2015) which has found that work pressure is made worse by a perceived need to repress emotions in order to remain ‘professional’. McPherson et al (2015) support mindfulness as a practice which improves the ability of those providing dementia care to be aware of their own feelings and accept them. This is supported by reports from elsewhere that this results in the care provider being able to care for others in a way which more connected emotionally and less mechanical (Hurley et al 2014; Mackenzie & Poulin 2006). It is therefore suggested here that mindfulness practice forms an important part of developing a virtue of receptivity.
Being connected to the emotions is the first stage in order to develop a virtue of receptivity but empathy is required which is able to appreciate someone else’s experience and respond in a way which reflects that appreciation. As Slote (Slote 2015: 5) argues:

‘There are known to be two types of empathy: the projective kind, which involves being able to get inside the heads of others; and the associative or receptive kind, which involves actually identifying with the other person, actually seeing things, however briefly, from their point of view. The con artist who knows how to get into other people’s heads and who is good at reading what they are thinking or feeling doesn’t actually identify with the other person and their feelings/beliefs.’

When applied to dementia care this suggests that every effort has to be made to imagine what it is like to be in that particular individual’s situation. In ethically challenging situations it is therefore essential to engage with the perspective of those receiving care.

This means that in an ethically challenging situation, the aim is to first put yourself in the position of those being affected. This involves imagining what it might be like from their perspective. Some exercises may be helpful.

- Role play where people put themselves in the position of someone with dementia.
- Use case studies and ask people to imagine both a receptive and unreceptive response.

For professionals, clinical supervision may also help people to reflect on their level of receptivity. Care providers in a non-work context might seek assistance from other care providers or support groups.

8.6.2 CARE IN A SUPPORTIVE SOCIOPOLITICAL CONTEXT

Support is a central part of providing good care. This is why sociopolitical justice and mutuality forms the basis of the ethical model. This part of the programme will focus on how ethical care can best be promoted. A number of factors are relevant.

Firstly, there are the broad political and organisational factors. As both Paley (2014) and McPherson et al (2015) point out, compassion deficit is not the source of unethical care when it is caused by issues such as poor staffing, management mechanisms or
other problems of a sociopolitical nature. As such, it is essential that care providers are supported by society and organisations to care ethically.

Secondly, there are relationship factors at the micro-level. This involves factors such as how care providers support each other within a team. It also involves the nature of the care relationship itself as well as the appropriate involvement of nearest and dearest in decision-making.

The overall aim is to support ethical care for the care receiver. This needs to be an aim shared at all levels. Those involved in care may wish to ask the following questions.

- What are the sources of support that care providers (or you as care provider) can draw on?
- How can people be best supported to provide care? If part of a team, what can we do to support each other?
- Reflect on vulnerability in the caring relationship and whether power is used appropriately.
- How can the environment be improved to better support care?
- What political changes might result in better resources for providing care?

It needs to be recognised that some organisational or broader sociopolitical problems may be outside of the influence of individual care providers. However, being aware of such limitations is nonetheless an important consideration both in making ethical decisions, and feeling comfortable with the decision made. Decisions have to be made in the context that care providers find themselves, not an ideal world. Though it is important to keep ideals in mind and part of a wider ethical approach might involve campaigning for changes to improve the situation.

The issue of power is also central here. Individual care providers may lack power to change the sociopolitical situation they find themselves in. However, care receivers often find themselves in a vulnerable and powerless position also. The response to vulnerability has been discussed in the thesis. For those who wish to promote independence as an ideal, empowerment may be seen as the logical solution to disempowerment. However, independence has been criticised in this thesis as an
unrealistic notion for human existence, particularly for those with dementia. Instead we find ourselves in a world of risky interdependence where we each have to trust each other and accept that we all are, to some extent, vulnerable. The response to vulnerability must therefore be a positive one that cultivates compassionate and appreciates mutual support rather than shunning it as weakness.

When making a decision using the model, negotiation may well be necessary along with compromise with other affected parties the process. Negotiation and compromise may suggest to some that the best or right answer has not been followed. However, this thought would not be in tune with overall approach of the model. Both a Humean view of virtue ethics and the ethics of care suggest it is an acceptable situation for more than one answer to present itself. This can be referred to as a ‘blameless diversity’ of moral options (Garrett 2015).

8.6.3 USING ETHICAL PRINCIPLES

Potentially this is the most theory dense aspect of the model. As such it is envisaged that the theory involved can be engaged with at different levels depending on people’s levels of knowledge.

At the basic level, it is assumed that everyone with normal cognition has the ability to be a moral agent. Following the discussion in Chapter 7 (7.2.1), it might also be supposed that there is a form of common morality that majority of people hold (Beauchamp and Childress 2013). As such people tend to make ethical choices on a daily basis, such as whether to own up to wrongdoing, share an ice cream, jump a red light etc. People will have found a way of balancing these decisions, which may be simply using the Golden Rule, treating everyone as they would wish themselves be treated. Though, participation in this ethical education programme would introduce some further options that may be of assistance.

At an intermediate level, the four principles framework of Beauchamp and Childress can be looked to for guidance. As discussed in depth, this involves balancing four principles: respect for autonomy, nonmaleficence, beneficence and justice. People would be made aware of the idea that these principles are non-absolute and need to be balanced. Examples real or imagined could be used to see how the principles might be employed.
At a more advanced level, the preferred approach is to use principles based on the Triple Theory of Parfit (2011). It is accepted that the concepts involved here are more complex. Fundamental to this approach is the claim that an act is wrong only when it is disallowed by a principle that will make things go best overall and can be both willed by all and not be reasonably objected to. The use of academic language may make this approach unattractive to some. Nonetheless, it does not seem wholly unrealistic to imagine a care provider considering whether an action conforms to a principle that is rational, justifiable to others and makes things go best.

8.6.4 MAKING ETHICAL DECISIONS

This leads to the core of the ethical model – the care response. The role of character comes to the fore in exercising judgement, both in terms of which course of action to choose and also how the decision is applied. Central to this process is asking the question

What would a good care provider do?

Professional groups may wish to the substitute the term care provider with a professional title. The model is flexible enough to allow for this as it is still consistent with the overarching aim which is to support people to be the best care providers they can be. It has already been argued that this requires a virtue of receptivity. Along with this the idea needs to be instilled that being a receptive care provider is a valuable occupation worthy of development.

An important part of this process is looking to exemplars. As discussed in Chapter 5 (5.4.4), these exemplars can be found in a variety of places and roles; they may be people from our everyday lives or those we know through literature. To help people with identifying exemplars the following question might be asked:

Think of one or more people who are an inspiration to you in terms of how they care for others? They may real or from literature.

This may then be followed up with a question such as

Return to one of the difficult ethical situations we have discussed. Imagine how your exemplar might respond in such a situation.
All of the elements can now be pulled together and a response made based on either the academic or simplified version of the ethical model as shown in Figures 4 and 5.

An education programme, based on the outline here, is proposed as the main way that the findings of this thesis could be implemented. There are a number of recommendations which also follow from the arguments made in the thesis.
9 RECOMMENDATIONS AND CONCLUSION

9.1 RECOMMENDATIONS

Recommendations in the following areas can be made:

Philosophy of the ethics of dementia care

1) Personhood as a moral status should not be the primary focus for ethical dementia care. The emphasis needs to be on emotions and interdependent relationships not the promotion of independence or individual choice (3.6.1)(3.7)(4.9.1)(5.5)(6.2.1)(8.4).

2) The term dignity expresses intuitive ideas that matter deeply to people and should not be dismissed. However, what people understand by the term varies greatly and is relative to culture. Care responses which look to dignity for inspiration need to be mindful of this (4.8).

Providing ethical dementia care

3) Emotions should form a central place in the ethics as well the general practice of dementia care. (6.5.1)

4) The virtue of receptivity should be the central virtue for dementia care. Care providers need to look for exemplars of receptivity in life and literature for inspiration and guidance. It is suggested that mindfulness practice forms an important part of developing a virtue of receptivity (5.5)(6.4)(6.5)(8.3.3)(8.6.1)

5) Principles should be seen as part of a pluralistic ethical approach which supports care providers to be the best care providers they can be. (7.7)

Social policy

6) It is necessary to improve sociopolitical conditions by raising the status of care in society as well as by promoting mutuality and negotiation in caring encounters (6.3) (6.4).

7) Advance decisions are an unreliable way of maintaining autonomy. Advance decisions to refuse treatment should be treated with caution and not given the same authority as contemporaneous refusals of treatment. (2.9)
Implementation and future research

8) The ethical model will be implemented by the development of an ethics education programme that could be made available in a range of settings and formats in order for it to reach the widest possible audience of dementia care providers (8.6).

9) Future research will test empirically whether the ethical model and the associated education programme are understandable across a range of care providers and if it is found to be useful in promoting ethical dementia care.

9.2 OVERALL CONCLUSION AND ORIGINAL CONTRIBUTION

The research question asked which philosophical approach provides the best foundation for the ethics of dementia care. In order to answer this question, a number of philosophical approaches have been evaluated.

Overall, it has been argued that personhood as a moral status should not be the primary focus for the ethics of dementia care. How best to construct, regain or maintain personhood in a broader sense might be useful questions to consider in terms of a therapeutic response to dementia. However, in terms of an ethical model, a more promising and inclusive route is to provide care for people in a way that does not require an answer to the question of whether personhood is present.

Instead, it is argued that emotions should form a central place in the ethics of dementia care. As a result, the term emotion-centred care might more accurately describe this new approach. It aims to nurture the good character of care providers so they can care for people in a way which is both receptive and principled.

The ethical model represents graphically the conclusion of this thesis. The ethical model demonstrates an original contribution to knowledge in the area. The central role of a virtue of receptivity, based on the work of Slote has not previously been applied as philosophical approach for the ethics of dementia care. Furthermore, it is a novel move to then combine this with both principle-based ethics and an ethics of care approach. Personhood not being at the centre of the ethical approach also marks a somewhat radical departure due to the central place that the concept has held discussions about dementia care for many years.
It is appreciated that harmonising such a broad range of philosophical ideas into the model may challenge those who believe that these ethical theories cannot be compatible with one another. This thesis has presented a number of arguments as to why this pluralistic approach is justified conceptually. These stand as its defence.

Whether such a model can be understood and used effectively by care providers is a separate but equally important consideration. The model and the proposed ethics education programme have been designed to be sensitive to this. However, whether either will be practicable is an empirical question that would be the subject of further research.

The recommendations outlined above flow from the arguments that have produced the ethical model. It is asserted that following the recommendations above will produce an ethics for dementia care which meets the challenges raised by the condition better than previous frameworks. More broadly, the model also promotes caring as an essential part of society which needs to be valued and supported as a mutual endeavour.

Dementia may or may not touch our lives directly. Nonetheless, we all need care at times, and we should hold in high esteem those who choose, often selflessly, to provide care to people at the time of their greatest need.

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APPENDIX A – CARE PROVIDER BEHAVIOURS RESULTING FROM A MALIGNANT SOCIAL PSYCHOLOGY

1. Treachery
2. Disempowerment
3. Infantilization
4. Intimidation
5. Labelling
6. Stigmatization
7. Outpacing
8. Invalidation
9. Banishment
10. Objectification
11. Ignoring
12. Imposition
13. Withholding
14. Accusation
15. Disruption
16. Mockery
17. Disparagement

(Kitwood 1997:46-47)
APPENDIX B – SIX COMPONENT ETHICAL FRAMEWORK FOR DEMENTIA PRODUCED BY THE NUFFIELD COUNCIL ON BIOETHICS

Dementia: an ethical framework (Box 2.1)

Component 1: A ‘case-based’ approach to ethical decisions: Ethical decisions can be approached in a three-stage process: identifying the relevant facts; interpreting and applying appropriate ethical values to those facts; and comparing the situation with other similar situations to find ethically relevant similarities or differences.

Component 2: A belief about the nature of dementia: Dementia arises as a result of a brain disorder, and is harmful to the individual.

Component 3: A belief about quality of life with dementia: With good care and support, people with dementia can expect to have a good quality of life throughout the course of their illness.

Component 4: The importance of promoting the interests both of the person with dementia and of those who care for them: People with dementia have interests, both in their autonomy and their well-being. Promoting autonomy involves enabling and fostering relationships that are important to the person, and supporting them in maintaining their sense of self and expressing their values. Autonomy is not simply to be equated with the ability to make rational decisions. A person’s well-being includes both their moment-to-moment experiences of contentment or pleasure, and more objective factors such as their level of cognitive functioning. The separate interests of carers must be recognised and promoted.

Component 5: The requirement to act in accordance with solidarity: The need to recognise the citizenship of people with dementia, and to acknowledge our mutual interdependence and responsibility to support people with dementia, both within families and in society as a whole.

Component 6: Recognising personhood, identity and value: The person with dementia remains the same, equally valued, person throughout the course of their illness, regardless of the extent of the changes in their cognitive and other functions.

Nuffield Council on Bioethics (2009a: xvii)