

ASSISTED DYING; AN ETHICS OF CARE PERSPECTIVE

by

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Abstract

The aim of this thesis is to reflect the role of care in response to requests for assistance to die. This thesis will seek to illustrate that it is fundamental that regulatory frameworks concerning assisted dying should attend to the reality of care. In the first chapter, this thesis will establish a care-based ethic which reflects assisted dying. Building on this argument, this thesis then moves to an analysis of the current regulatory frameworks associated with assisted dying namely; the failed attempt at statutory legislation and the Director of Public Prosecution Guidelines. This thesis will then analyse contemporary cases concerning the minimally conscious patient and judicial reasoning in the most recent Supreme Court case, *Nicklinson*. Ultimately, this thesis will demonstrate that a regulatory framework concerning assisted dying must attend to the realities of care in both the private and public domain and recognise the influence of care on both legislative safeguards and the state provision of care.

To Dad, thank you for your continued encouragement, support and guidance. To Mum, thank you for the sacrifices you have made, your kindness and unfaltering patience. And to my family and friends. Thank you for always being there.

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INTRODUCTION

Over the last two decades assisted dying has seized public, judicial and parliamentary attention. As the recent case of *Noel Conway v Secretary of State for Justice*¹ illustrates, requests for the legalisation of assisted dying continues with some momentum. This is due to medical advances which enable individuals to live longer, yet with a reduced and often declining quality of life. Because of these medical advances an assisted death has been advocated as an option for these individuals. Notably in 2014, the Supreme Court disallowed the appeal made by Mr Nicklinson to end his life which required assistance from a health care professional². However, two of the nine Supreme Court justices were willing to make a declaration of incompatibility and three other justices had temporal or evidential issues with the appeals raised. *Nicklinson* relied on fundamental human rights protected by EU law and followed a trend to establish rights-based arguments in the health care setting.³

Given these two above points, it is arguable whether the legalisation of assisted dying is imminent. Yet since 2014 only two cases (*Conway* being one) have come to judicial attention.⁴ These cases reflect rights-based arguments found in *Nicklinson* and rejected parliamentary bills.⁵ As a result, there is now an increasingly complex and inconsistent system of implicit and informal regulation. I argue that the practice of care and relational dynamics, which are inextricably linked to the everyday lives of those who require assistance to end their life, is ignored in both parliamentary debate and judicial reasoning. Though both

¹ [2017] EWHC640 (Admin).

² *R (on the application of Nicklinson and another) (Appellants) v Ministry of Justice (Respondent)* [2014] UKSC 38 [2014] UKSC 38. The facts of this case will be discussed further in Chapter Two.

³ See further; J McHale and T K Hervey, *European Union health law : themes and implications* (2015) CUP.

⁴ *Conway* (n1).

⁵ Assisted Dying Bill [HL] 2013-14

parliament⁶ and the courts⁷ have dismissed any formal legal regulation for assisted dying, regulation of this scenario remains implicit, complex and overlooks the practice of care.

The primary aim of this thesis is to explore the practice of labour associated care, be it physical, emotional, fiscal and organisational, on the individual who requests assistance.

From this perspective, this thesis will map the type of care and relational dynamics which are appropriate to the care actors and state agencies involved with the individual who requests assistance. This is an important perspective to take as it offers a new approach in understanding the effects of regulation on the individual who requests assistance and how a care-based ethic can reconceptualise our approach to assisted dying.

This thesis will therefore begin with an evaluation of the current law concerning assisted dying. The aim of this chapter is to highlight the *de facto* legalisation caused by the Director of Public Prosecution's guidance in 2014. The chapter will first examine the attempts of legislation in Parliament. The "eligibility criteria" contained in these failed Bills will be evaluated in order to establish which individuals should be served by assisted dying frameworks. This will include an analysis of how suffering is conceptualised and the unnecessary association this has with medical diagnoses.

It will then be demonstrated that under the Director of Public Prosecution's (DPP) guidance a specific circumstance which is inextricably linked to (nuclear) familial assistance and the concept of compassion has been established. What is unclear is the type of assistance which is permissible. Additionally, individuals who do not have access to familial assistance are without assistance and support. Ultimately in Chapter One I will argue that the DPP's guidelines conceal the justificatory argument behind the guidelines which is the right to an autonomous decision to end one's life. Where appropriate I will use the example of

⁶ Parliament have debated assisted dying at least six times in the last nine years. See further; *Nicklinson* (n2).

⁷ *ibid.*

individuals who were living with dementia to highlight the role of autonomous decision-making and suffering as part of the current regulatory frameworks.

In Chapter Two it will be illustrated that the type of care appropriate for the individual who requests assistance is dependent on each care provider. This will be achieved by first arguing that the type of care-based ethic appropriate for the individual that requires assistance to end their life is premised on an understanding of process-based autonomy. Based on Friedman and Meyer's respective theories, the reflective and relational qualities that are part of a process-based autonomy framework will be discussed. Following this, I will establish a gender-neutral and non-normative understanding of familial care and discuss how this approach recognises the realities of caring for the individual who requests assistance. This discussion has the potential to broaden regulatory framework. This chapter will also establish a principled approach for health and social care professionals. By using this approach, the current perspective of care professionals' roles in response to the individual who requests assistance will be analysed. This will result in arguing that health and social care professionals should, under a principled care-ethic, play a more substantial role in supporting the individual who requests assistance. This chapter's analysis will also include an analysis of how the state facilitates care both in the private and public domain and in turn how this produces normative definitions of care practices. By applying a care ethic to separate care actors this chapter will illustrate how the integration of these care roles play an important part in the assisted dying debate which will be built on in further chapters.

In Chapter Three discussion will turn to contemporary medical law cases concerning individuals in a minimally conscious state (MCS). Here I will evaluate the conceptualisation of withdrawing treatment as a model of passive euthanasia in judicial reasoning. To achieve this, I will rely on an analysis of the Mental Capacity Act (MCA) and how this dictates

judicial interpretation. This will primarily focus on the best interest test at s4 of the MCA.⁸ By focussing on this test and using the reasoning developed in *University Hospital NHS Foundation Trust v Aintree*⁹ and *Briggs v Briggs* respectively¹⁰ I will argue that a substituted judgment test is increasingly being deployed as a mechanism to determine what is in the best interest of the patient. The final part of this chapter will be given over to an analysis of the Supreme Court decision in *Nicklinson*.¹¹ The discussion of judicial reasoning in this case is used for two reasons. Firstly, it highlights the theoretical arguments concerning vulnerability and the risk of duress when regulating assisted dying. Secondly, the circumstance of Mr Nicklinson and his fellow appellants illustrate important legal inconsistencies between how we perceive and apply the law to individuals who have capacity but refuse treatment, and those individuals who lack capacity to do so. This issue indicates how vulnerability arguments apply normative expectations of those with disabilities. Ultimately in Chapter Three I will demonstrate that the regulatory framework concerning assisted dying ignores the care-based and relational realities of requests for assistance.

In the final chapter the care-based ethic established in Chapter Two will be applied to the current legal framework concerning assisted dying discussed in Chapter One. I will use four paradigmatic scenarios concerning requests for an assisted death. This will begin with individuals who have both physical capacity and mental capacity. In discussing this scenario, I will apply a care-based approach to the state's responsibility for care. I will argue that a care-based approach would not support request for assistance in this instance. I will then focus on the individual who lacks physical capacity but has mental capacity. This will be contrasted with individuals living with dementia and advance directives for requests for

⁸ Mental Capacity Act 2005 s4.

⁹ *Aintree University Hospitals NHS Foundation Trust v David James (by his litigation friend, the Official Solicitor), May James, Julie James* [2013] EWCA Civ 65

¹⁰ *Briggs v Briggs* [2013] UKSC 67

¹¹ *Nicklinson* (n2).

assistance to die. Additionally, I will develop a framework to establish how a process-based approach to autonomy and capacity can be incorporated into regulation. The third part of this chapter will then focus on the complexities of advance requests for assistance from those who are living with dementia. I will use an analysis of how a care-based approach can balance previous wishes and feelings against current wishes and feelings. The final part of this chapter will then focus on assisted dying in respect of individuals who lack both mental capacity and physical capacity such as MCS or PVS. This will include an analysis of how various care theorists conceptualise “intending death” and the emphasis placed on a substituted judgment above a best interest test. I also include a discussion of the role of health care professionals in response to requests for assistance and how recognising relational interaction could support arguments for a rights-based analysis.

While the ultimate approach in this thesis is to understand the care-based reality of the individual who requests assistance to end their life, the approach taken extends beyond just this. My aim is to draw out the legal and ethical nuances between the paradigmatic scenarios that exist in the context of assisted dying. By doing this I will illustrate that the traditional rights-based approach to regulating assisted dying is inferior to a care-based approach, even if the latter requires a more complex application of legal regulation. Death, dying and care are not isolated phenomena, they are an integrated set of practices and ideals. Care should not be side-lined in the assisted dying debate. Rather, care is an integral component in reconceptualising a regulatory framework for assisted dying.

CHAPTER ONE: WHAT ARE THE CURRENT LEGAL FRAMEWORKS CONCERNING
ASSISTED DYING: STATUTORY REGULATION

1. Introduction

This section will analyse the legislative frameworks that govern assisted dying law. This will be achieved by first discussing the historical bases to the attempted legislative Bills. This analysis will critique the criteria established in such bills. Building on this, the chapter will also discuss the Director of Public Prosecution's guidelines as an additional aid to the current legislative framework. Using the Decision on the Death of Daniel James published by the DPP this chapter will critique the use of compassion, the role of the family and the concept of assistance concerning requests for assistance.

2. The Historical Background of Assisted Dying Law

Today, with advances in science and healthcare allowing individuals to live longer, yet often with a declining quality of life, choosing to die often becomes a desired option.¹² The current prohibition on assisted suicide therefore becomes an issue. The historical context of assisted dying legislation will be provided here in order to analyse the current assisted dying regulation in the remaining part of this chapter. Section two of the Suicide Act 1961 states that criminal liability for complicity in another's suicide will be established if the assister; '(a) D does an act capable of encouraging or assisting the suicide or attempted suicide of another person, and (b) D's act was intended to encourage or assist suicide or an attempt at suicide.'¹³ The Suicide Act decriminalised suicide itself. However in England and Wales assisting someone to die remains illegal and carries with it a maximum of fourteen years in prison.¹⁴ There have been relatively few prosecutions under the Act, with only one case of

¹² See further; A Chapple *et al*, 'What people close to death say about euthanasia and assisted dying: A qualitative study' (2006) *JMed* 32 706-710.

¹³ The Suicide Act 1961 s2.

¹⁴ *ibid* s.1.

attempted suicide successfully prosecuted in 2013.¹⁵ Although the courts have been reluctant to make statements in advance of particular acts, criminal liability has been broadly defined as ‘specific assistance to a particular individual who considers suicide at that time.’¹⁶ Section 2(4) requires prosecution ‘by or with the consent of the Director of Public Prosecutions.’¹⁷ The DPP’s specific guidelines will be evaluated in section four.

Between 2003 and 2006, Lord Joffe unsuccessfully made four attempts to legislate in favour of assisted dying.¹⁸ In 2015 Lord Falconer’s Bill (Assisted Dying (No1) Bill) was introduced in the Lords.¹⁹ The Bill drew heavily from The Death with Dignity Act in force in Oregon²⁰ and took much the same approach to Lord Joffe’s Bill. The Act would have legalised the provision of medication by a registered medical practitioner or a registered nurse to those over eighteen with capacity, suffering from a terminal illness with a six-month prognosis or less to enable the individual to end their life. The theoretical underpinning of the Bill reflects the capacity-based difficulties which arise when attempting to regulate assisted dying. As Otlowski argues, the prospect of future legislation will only be successful if it is justified by self-determination.²¹ Otlowski further states that the principle of liberty should be the sole consideration when regulating assisted dying. This is because the individual’s choice is premised on the subjective assessment of their own particular situation. The only limit to this

¹⁵ DPP, *Policy for prosecutors in respect of cases of encouraging or assisting suicide* (CPS, October 2014)

<http://www.cps.gov.uk/publications/prosecution/assisted_suicide_policy.pdf> accessed 13 March 2017.

¹⁶ See further; *Attorney General v Able and Others* [1983] QBD 28 APR. In this case the general distribution of a booklet which described various way of committing suicide was not an offence. Criminal liability would only be found if the booklet was given to a particular individual who was considering suicide at that time.

¹⁷ The Suicide Act 1961 s2 (4).

¹⁸ Assisted Dying for the Terminally Ill Bill [HL] 2003-2004; Assisted Dying for the Terminally Ill Bill [HL] 2005-2006.

¹⁹ Assisted Dying Bill (No1) [HL] 2015-16.

²⁰ Death with Dignity Act 1997.

²¹ M Otlowski, *Voluntary Euthanasia and the Common Law* (OUP 1997).

justification is a lack of capacity.²² This autonomy-based principle has often been conceptualised by theorists as a rights-based argument.²³ Yet as Lewis highlights, rights-claims are limited due to how these individual rights have the potential to conflict and how when applied, they can be indeterminate and ignore the care-based interrelatedness that exists between individuals.²⁴

With 330 votes against Lord Falconer's Bill compared to 118 in favour, it appears unlikely that the issue of assisted dying will arise in Parliament for considerable time. In 2010, the Scottish Parliament also rejected a similar Bill. However, I argue that we are fortunate that The Assisted Dying Bill (No1) Bill was rejected at its first reading for three distinct reasons. These are the eligibility criteria; the concept of suffering, and thirdly the application of capacity. These reasons highlight how the individual who requests assistance has traditionally been perceived in the legislative environment, and highlights the theoretical arguments briefly discussed above.

Terminal Illness

The eligibility criteria of terminal illness are an important issue to raise as it restricts who would be eligible for assistance. The suggested "eligibility" criteria were as follows:

- (a) a diagnosis by a registered medical practitioner as having an inevitably progressive condition which cannot be reversed by treatment ("a terminal illness"); and
- (b) as a consequence of that terminal illness, is reasonably expected to die within six months.²⁵

Firstly, these criteria would have only served a small percentage of the population and excludes those who live with degenerative or chronic conditions. Secondly, it has been demonstrated that in other jurisdictions where both palliative care and assisted dying have

²² *ibid* 188-191.

²³ See further; P Lewis, *Assisted Dying and Legal Change* (OUP, 2007).

²⁴ *ibid*.

²⁵ Assisted Dying Bill ((No1) (n19) s2.

been available, individuals in the last six months of their life chose to make use of palliative care options over an assisted death. It is understandable that the restrictive criteria of The Assisted Dying (No 1) Bill was a realisation that if legislation were to be passed, it would be premised on the strictest of criteria and that either judicial engagement or further Bills could have expanded the original legislation. Most importantly though, in cases that have come before the courts,²⁶ all concerned individuals living with a degenerative or chronic illness. In fact, the (unofficial) Commission on Assisted Dying Report²⁷ predominantly focussed on the experiences of those with a degenerative illness, with this group deemed as most in need of assistance to end their own life.

Unbearable Suffering – is it always up to medicine?

Historically, in the UK, assisted dying has been perceived as inextricably linked to medical futility and understandings of suffering. The (unofficial) Commission on Assisted Dying and the Assisted Dying (No 1) Bill made a presumption that assisted dying is only appropriate when the individual has an ‘inevitably progressive condition which cannot be reversed by treatment.’²⁸ The Commission’s inclusion of suffering reflects a transition from the traditional moral paradigm of the sanctity of life to the equivalently traditional moral paradigm of quality of life arguments.²⁹ Proponents of the principle of the sanctity of life, such as Keown, argue that human life is intrinsically valuable in and of itself and as such the intentional termination of life is morally reprehensible.³⁰ In contrast the principle of quality of life suggests that life is instrumentally valuable based on the concept that it is our experiences

²⁶ See further; *R (Pretty) v Director of Public Prosecutions* [2002] 1 AC 800; *R (Purdy) v DPP* [2009] UKHL 45; *Nicklinson* (n1).

²⁷ Commission on Assisted Dying 2012
<https://www.demos.co.uk/files/476_CoAD_FinalReport_158x240_I_web_single-NEW_.pdf?1328113363> accessed 13 March 2017.

²⁸ Assisted Dying Bill ((No1) (n19) s2.

²⁹ See further; J Keown, *Euthanasia, Ethics and Public Policy: An argument against legislation* (CUP 2002).

³⁰ *ibid.*

that shape the value found in our existence. In the proposed legislation, there was no mention of the wider context of the effects of terminal illness (let alone a degenerative diagnosis) and how this affects the individual's quality of life. The Bill failed to reflect the relational, social and financial life interests (although this list is not limited to these factors) that are inextricably linked to life-limiting diagnoses and quality of life assessments. Instead medical futility is viewed as the determining factor in choosing to die.

By incorporating an understanding of suffering into an assessment of assisted dying arguments, a broader understanding of what is conducive to a (subjectively) 'good life' can be understood. As Price has argued, suffering can emanate from an entirely non-medical cause.³¹ Price also argued that this has the potential to threaten the professionalism of healthcare professionals as if medicine's ability to "heal" is equal to its power to "kill" then the healthcare professional becomes a 'morally neutered technician.'³² However, I argue that the healthcare professional's medical role remains an important arbiter in how far suffering is determined to be subjective.

Interestingly, the (unofficial) Commission on Assisted Dying Report placed great emphasis on the concept of the subjective experience of suffering but did not include the wide range of factors that influence a quality of life assessment as in the suggested legislation. In contrast, both the Netherlands³³ and Belgium³⁴ legislate in favour of assisted dying premised on criterion of individual suffering. In the Netherlands the patient's suffering must be lasting and unbearable. It is arguable that a diagnosis which results in unbearable suffering will undoubtedly have an effect on relational dynamics, life plans or goals, personal values and financial concerns that the dying individual holds. These examples acknowledge and

³¹ D Price, 'What shape to euthanasia after *Bland*? Historical, contemporary and futuristic paradigms' (2009) LQR 125.

³² *ibid.*

³³ Termination of Life on Request and Assisted Suicide (Review Procedures) Act (Netherlands) 2002.

³⁴ The Euthanasia Act (Belgium) 2002

influence a subjective understanding of what it means to suffer. However, as the Dutch case of *Brongensma*³⁵ illustrates, if there is no somatic or physical illness as a basis for suffering, existential suffering alone is not grounds for assisted suicide. Therefore, suffering is constrained by whether it originates from a medically classified disease. Though suffering may be constrained as a consequence of a medically classified disease, it does not necessarily mean that the broad scope of factors that influence a subjective quality of life assessment cannot be utilised. However, there is potential to objectively assess the concept of suffering premised on a medically classified disease. This argument is supported by Gevers' empirical study into physician's and patient's views of suffering in light of requests for assistance to die.³⁶ Gevers' found that health care professionals often took a narrow view of the significance of the suffering and also often based this on the physical symptoms the patient was experiencing. As such, the non-physical suffering connected with the individual's physical symptoms were not recognised.

This comparison briefly illustrates how the reasons behind a desire to end one's own life prove to be much broader in scope than just the symptoms of a medically recognised illness. However, a subjective assessment of what it means to suffer will always be underpinned by an objective medical assessment. The objective-subjective relationship will undoubtedly continue to make understanding the concept of suffering complex. Yet the concept of unbearable suffering should not be ignored. This concept does take steps to widen the scope of who would be eligible for assistance but also reflects the realities of how, as individuals, when we are affected by illness we make decisions about the values and experiences of life which the previous and narrow attempts at legislation have ignored.

³⁵ HR 24 Dec 2002 (LJN AE8772).

³⁶ JK Gevers, 'Legislation on euthanasia: recent developments in The Netherlands' (1992) *J Med Ethics* 18 (3).

Autonomy and capacity

This section will discuss how we legislate in respect of individuals who would typically be deemed as “lacking” capacity. Lord Falconer’s Bill referred to capacity as defined by the Mental Capacity Act.³⁷ Traditionally, capacity criteria for the individual who requests assistance has been narrowly constructed and have avoided the complexities of enabling autonomous decisions for individuals with intellectual or psycho-social disabilities.

Dementia provides a pertinent example of why the consideration of autonomy is important to the legal frameworks concerning the individual who requests assistance. This is because dementia is defined as a terminal and degenerative illness and therefore would satisfy the criteria in Lord Falconer’s Bill. However, since a diagnosis of dementia means a progressive loss of capacity, this naturally raises questions about the relationship between capacity and assistance.³⁸ It is unlikely that in the last six months of life, the individual living with dementia would satisfy the capacity requirements which have continually been emphasised as the cornerstone of assisted dying legislation. The only option available that the individual with a diagnosis of dementia has is to end their life earlier (when they have the capacity to do so) without assistance.

Yet Article 12 of the UN Convention on Human Rights of Persons with Disabilities provides that everyone has the right to equal treatment before the law which is inclusive of those who have intellectual or psycho-social disabilities. This therefore suggests that such individuals have a right to support in decision-making but how far this extends to a right to an assisted death is uncertain.³⁹ Indeed previous attempts at legislation have ignored the role that precedent autonomy could play. For example, for the patient in later stages of dementia a

³⁷ Assisted Dying Bill (No 1) (n19) s12.

³⁸ M Annear, ‘What should we know about dementia in the 21st Century? A Delphi consensus study’ (2015) *BMC Geriatrics* 15(5).

³⁹ See further; E Peel and R Harding, ‘A Right to ‘dying well’ with dementia? Capacity ‘choice’ and relationality’ *Feminism & Psychology* 2015 25 (1).

framework which would honour previous wishes (inclusive of assistance to die) could be developed. As Hughes argues ‘by allowing the patient to retain some degree of metaphysical authority, advance directives can be seen as means of preserving dignity. In this sense, they are a form of resistance against extreme vulnerability.’⁴⁰ Nevertheless, dementia patients may still have the ability to express preferences and opinions, even if these differ from the wishes stated in the advance directive.

Dworkin has argued in favor of upholding advance directives for patients with dementia.⁴¹ This argument is premised on the concept that the individual living with dementia cannot recognise their life as a whole and therefore cannot develop what Dworkin defines as criterial interests; the values and life goals which shape our existence. By contrast Dworkin argues that the pleasures of everyday life (experiential interests), although valuable, should not be prioritised above criterial interests when determining whether an advance directive should be applied. Dworkin describes the patient with advanced dementia as, ‘ignorant of self – not as an amnesiac is, not simply because they cannot identify their pasts – but more fundamentally because they have no sense of a whole life, a past joined to a future, that could be the object of any evaluation or concern as a whole.’⁴² Therefore, to honor previous wishes (inclusive of a request for assistance to die) is the only way to respect the autonomy of the individual. Yet Dresser has argued that we should respect the current views of individual living with dementia. Dresser contends that in the latter stages of dementia the individual is so cognitively isolated from their previous autonomous self that their previous wishes (or

⁴⁰ A Hughes, ‘No man is an island: relational autonomy and dementia’ (2013) *Elder Law Journal* (3).

⁴¹ R Dworkin, *Life's Dominion : An Argument about Abortion, Euthanasia and Individual Freedom* (Vintage Books 1990) 201–202.

⁴² *ibid.*

criteria interests) do not carry any weight.⁴³ Although making opposing arguments, both Dworkin and Dresser's positions are premised on a one-dimensional perspective of the individual living with dementia; the individual *then* and the individual *now*. In response to this, Hughes has argued that a relational approach could be applied whereby both the *then* and *now* are incorporated into whether an advance directive should be upheld as 'our emotions and experiential interests are important manifestations of our character.'⁴⁴ Even though a dementia patient may not fully understand their situation or may not be able to place their feelings or preferences within the greater scheme of their lives, these views are reflective of the person and cannot simply be dismissed. Even if the patient has executed an advance directive, if the patient seems happy and free from distress, it is unlikely the family would encourage that the advance directive be upheld. This is particularly likely where that treatment is effective and minimally invasive, for example antibiotic treatment for a chest infection. For the carers and family members, the patient remains a mother, father, friend or sister, rather than simply a dementia sufferer. It is important to remember that such decisions have enormous impact on a person's family and friends.⁴⁵

This example also reflects the current societal response to individuals living with dementia. As Jaworska notes, it is unlikely that a medical practitioner would be willing to administer a lethal dose of medication to a patient who can seemingly take value from their current existence, albeit a different existence before living with the symptoms of dementia.⁴⁶

⁴³R Dresser, 'Dworkin on Dementia: Elegant Theory, Questionable Policy' (1995) 25 Hastings Center Report 32. For further examples see; J Herring, 'Losing it? Losing What? The Law and Dementia' (2009) CFLQ 3–28.

⁴⁴ E R Koppelman, 'Dementia and Dignity: Towards a New Method of Surrogate Decision Making' (2002) J Med Philos 27 (1) 75-76.

⁴⁵ A Hughes, 'No man is an island: relational autonomy and dementia'(n113).

⁴⁶ A Jaworska, 'Respecting the Margins of Agency: Alzheimer's Patients and the Capacity to Value'(1999) Phil. & Pub. Aff. (28)105.

Moreover, it is difficult to determine the true condition of the patient especially when the patient cannot communicate their feelings. The individual living with dementia may appear happy but cannot communicate their distress or discomfort or equally the patient living with dementia may not be able to remember discomfort long enough to communicate this to their carer. Therefore, because of the subjective nature of living with dementia and the highly complex assumptions that must be made I argue that this presents too many challenges to apply adequately precedent autonomy even if current wishes were also taken into account. This section has highlighted the three major arguments which define the individual who requests assistance: how we conceptualise illness; suffering, and autonomy. These issues will be, where appropriate, raised in the following section concerning the DPP's policy.

3. Director of Public Prosecution's Policy

It was not until 2009 and the case of *Purdy*,⁴⁷ that the House of Lords compelled the DPP to publish their prosecutorial policy. The DPP published a final policy in February 2010.⁴⁸ Since then, the DPP's prosecutorial policy has had a vast influence on the legal status of assisted dying with prosecution turning on the public interest stage. In 2014, the DPP's policy was updated in response to the second appeal in *Nicklinson* brought by the appellant known as Martin.⁴⁹ Martin sought an order for the DPP to amend the 2010 policy so that professional carers would not be prosecuted for assisting the suicide of Martin. In response, the DPP maintained that prosecution is likely if the assister was a healthcare professional or professional carer with a relationship of care and amended their policy to reflect this.⁵⁰ The DPP's Policy includes sixteen factors tending in favour of prosecution and six factors tending against prosecution. Reading these factors together, prosecution will be unlikely if the victim was over eighteen years old, had capacity (as defined by the Mental Capacity Act

⁴⁷ *Purdy* (n26).

⁴⁸ Director of Public Prosecutions, *Policy for Prosecutors* (n15).

⁴⁹ *Nicklinson* (n1) [3].

⁵⁰ Director of Public Prosecutions, *Policy for Prosecutors* (n15) paragraph 43(14).

2005), could not physically undertake the act which constituted assistance, and lastly the ‘victim’ made a voluntary, clear, settled and informed decision to commit suicide and clearly communicates this to the ‘suspect’ who is known to the ‘victim.’ Importantly, the ‘suspect’ must have been wholly motivated by compassion with their role deemed as ‘reluctant encouragement or assistance in the face of a determined wish on the part of the victim to commit suicide.’⁵¹

In 2008 and in an unusual step to take, the DPP published *The Decision on the Death of Daniel James*.⁵² This decision provides valuable insight into the evaluation of prosecutorial policy and will be used in this section to critique the DPP guidelines.

The Decision on the Death of Daniel James

Mr James was injured in a rugby training session which resulted in a dislocation of two vertebrae and spinal cord compression. Mr James was diagnosed as tetraplegic and was paralysed from the chest down but retained mobility in his shoulders, biceps and triceps. Within less than a year Mr James, aged 23, had attempted suicide on three separate occasions. It was at this point that Mr James contacted Dignitas in Switzerland. Mr James’s parents and a family friend aided Mr James by means of organisation of travel arrangements and accompaniment to Switzerland. On 12th September 2008, accompanied by his parents, Mr James attended a Dignitas clinic where a doctor assisted Mr James to die.⁵³ The DPP’s reasoning appeared to be motivated by three issues: satisfying that Mr James had capacity; the assistance provided by Mr James’s family and family friend at an evidential stage test,

⁵¹ *ibid* Paragraph 45(5)

⁵² Director of Public Prosecutions, *Decision on Prosecution – The Death by Suicide of Daniel James* (Press Release Crown Prosecution Service February 2008) <http://www.cps.gov.uk/news/articles/death_by_suicide_of_daniel_james/> accessed 13 March 2017.

⁵³ *ibid*.

and the assistance provided under the public interest stage of the test. The following sections will draw upon these issues in an analysis of the DPP's guidelines and the influence this has on current legal frameworks.

Though the DPP guidelines make it clear that their policy does not change the current criminal prohibition of assisted suicide in the UK, I will argue that the factors in favour and against prosecution provide a very clear scenario of *de facto* de-criminalisation of assisting someone to die.

What does assistance mean?

The DPP state that the type of assistance tending against prosecution is 'reluctant encouragement or assistance in the face of a determined wish on the part of the victim to commit suicide.'⁵⁴ In effect, though, the DPP plays a significant role in defining the acts which constitute assistance.

There is little case law to support the types of actions that fulfil the criteria for minor encouragement or assistance but in the DPP's discussion of the case of Mr James, assistance provided by Mr James's parents was described as 'towards the lesser culpable end of the spectrum.'⁵⁵ At the higher end of this spectrum the DPP placed the cases of *Wallis*⁵⁶ and *Hough*.⁵⁷ In the former, the defendant bought large quantities of aspirin and codeine, cough medicine and a bottle of vodka. The victim, who had struggled with drug addiction, then took these while the defendant sat with her. The defendant refused to call an ambulance for the victim and was described by the police as treating the circumstances of the death of the victim as a joke. In the latter case, the defendant agreed to supply a deadly number of tablets to an eighty-four-year-old woman who wanted to commit suicide after experiencing great

⁵⁴ Director of Public Prosecutions, *Policy for Prosecutors* (n15) para 45(5).

⁵⁵ *ibid.*

⁵⁶ (1983) 5 Cr App R (S) 342

⁵⁷ *R v Hough* (1984) 6 Cr App R (S) 406

unhappiness and suffering due to being partially blind, deaf and suffering from arthritis. The defendant spent a year trying to dissuade the victim but to no avail. The victim took the drugs and when she fell unconscious the defendant placed a bag over the victim's head in order to stop the victim breathing. In both cases the defendants were found guilty of assisting suicide under the Suicide Act 1961. It is clear why *Wallis* was found criminally liable; the defendant had encouraged rather than discouraged the victim's suicide for morally reprehensible reasons.⁵⁸ What is less clear is the moral reprehensibility of the defendant in *Hough*; there was evidently discouragement but it was found that placing a bag over the victim's head was, relative to providing the means to suicide, an act which was deemed as worthy of prosecution.

In the case of Mr James however, sending documentation, making payments to Dignitas in Switzerland, making travel arrangements and accompanying the individual on the flight was considered by the DPP as more than just minor acts but was not sufficient to prosecute and hints at *de facto* legalisation of "suicide tourism". The DPP's differentiation between organisational assistance (Mr James), part-physical assistance (*Hough*) and active encouragement of suicide (*Wallis*) legitimises assistance which is "administrative" in nature and perhaps best characterised as secondary assistance. Comparatively, first-hand assistance seems to support the physical acts as in *Hough* and *Wallis*. Consequently, it appears that assistance will not be prosecuted for those who can financially afford to travel abroad and have access to familial physical care-labour. Most of all though, the DPP's policy prevents the individual from dying, assisted, at home.

What does compassion mean?

⁵⁸ See further *R v McShane* (1977) 66 Cr App R 97. This case found a daughter guilty of trying to persuade her 89-year-old mother, who resided in a nursing home to commit suicide to gain inheritance.

Paragraph 45 (3) of the guidelines states that ‘the suspect was wholly motivated by compassion.’ Given that Lord Hope reasoned that the law should be read in conjunction with the DPP guidelines, it is arguable that the DPP’s policy has amended the 1961 Act by making compassion a definitional element of the offence.⁵⁹ Biggs notes that ‘the existence of compassionate motivation has been influential in the prosecutorial decision-making process for some time, despite its denial in criminal law doctrine.’⁶⁰ The DPP have not clarified how compassion is defined in this context and it is beyond the scope of this chapter to comprehensibly analyse the contributions to its meaning.

Though the DPP’s guidelines do not stipulate that a certain medical condition must be present, (it was discussed in the consultation process), the policy suggests that a medical condition underlies the basis of compassion.⁶¹ The tenth public interest factor tending in favour of prosecution is that the victim was ‘physically able to undertake the act that constituted assistance him or herself.’ This means that in instances such as Mr James, individuals who suffer from degenerative or paralysing injuries are deserving of enough compassion to assist them to commit suicide. The DPP described Mr James as a ‘dynamic, active, sporty, young man who loved travel and being independent.’⁶² I question that if Mr James had not been sporty or active but rather someone who enjoyed time indoors watching television whether there would have been less compassion owed because he could still enjoy a similar standard of activity before the accident which rendered him disabled. One can question that if Mr James had more mobility then the DPP would have viewed compassion as misplaced in this scenario. Though this factor is perhaps included to demarcate the difference

⁵⁹ C O’Sullivan, ‘Mens rea, motive and assisted suicide: does the DPP’s Policy go too far?’ (2015) *Legal Studies* 35 (1)

⁶⁰ H Biggs, ‘Legitimate Compassion or Compassionate Legitimation? Reflections on the Policy for Prosecutors in Respect of Cases of Encouraging or Assisting Suicide’ (2011) *Fem Leg Stud* (19) 47.

⁶¹ *ibid* emphasis added.

⁶² Director of Public Prosecutions, *Decision on Prosecution* (n15) paragraph 6.

between assistance and the practice of active euthanasia (even if this is voluntary) I argue that this factor has a more profound effect on the relationship between compassion and rights rhetoric in legal regulation.

As Lewis notes, the use of rights has dominated arguments concerning assisted dying.⁶³

Though Lewis fails to illustrate whether rights arguments have an overall benefit for legalising assisted dying, the discussion of rights draws parallels with Herring's discussion of compassion and legal rights. Herring argues that rights operate to draw boundaries around individuals.⁶⁴ I argue that viewing compassion as inherently linked to a physical disability operates to draw a rights-based boundary which presents individuals as having the right to self-determination and to act on this right. Not only does this categorise the type of physical disability appropriate for assisted dying but it also excludes individuals who suffer from dementia, who may be physically "fit" but are intellectually disabled. The DPP guidelines presume that those who have physical ability are able to end their life without help. By restricting the type of individual to those who are exceedingly physically disabled we seemingly view compassion as inextricably connected to a medical condition rather than the effects of that condition. By establishing a compassionate response as one justified by a medical condition with associated physical restrictions we run the risk that we normatively view physical disability as inextricably linked to suffering and the prospect of suicide. It is arguable that this approach encourages an incorrect societal understanding that disability is only physical which results in risk that disability becomes stereotyped in this way. Instead, a compassionate response to recognising physical restrictions must also recognise that rights

⁶³ P Lewis, *Assisted Dying and Legal Change* (n23).

⁶⁴ J Herring, 'Compassion, ethics of care and legal rights' (2017) *International Journal of Law in Context* 13 (2).

are also situated within relationships of care and are connected to a social, political and historical context.⁶⁵

Further, paragraph 45(4) states that the ‘suspect had sought to dissuade the victim from taking the course of action which resulted in his or her suicide.’⁶⁶ Lewis describes the DPP’s use of reluctance as ‘some sort of conscience-driven emotional difficulty’ in providing assistance. Although an extremely emotional situation, it should not necessarily be presumed that the assister does not want the individual to end their own life. This is not to say that they desire the death of the individual but it is to appreciate that the assister may agree that death is a better alternative than to continue living. O’Sullivan perceptively describes this as ‘hiving off cases where an accused benevolently assists another to commit suicide from those where an accused acted equally intentionally but was not entirely motivated by compassion. The latter are guilty of the offence, the former are actually or effectively exempted.’⁶⁷ In the Decision of Mr James, the DPP described Daniel’s parents as ‘particularly distressed by his wish to end his own life. They tried relentlessly to persuade him to not do so.’⁶⁸ The DPP’s policy imagines an idealised scenario, the assister does not want the individual to die but *obliges* nonetheless. I argue that agreeing with the dying individual that suicide is a more suitable alternative than suffering does not make compassionate assistance any less compassionate than trying to dissuade the dying individual to end their own life. As Herring argues, the law has the ability to influence societal functioning. Therefore, in agreement with Herring, the law’s influence should facilitate caring relationships wherever possible.⁶⁹ The DPP’s idealised scenario which creates an obliging assister fails to protect and promote caring relationships which are inclusive of an assister agreeing that death may be the best

⁶⁵ See further; *ibid*; S Sevenhuijsen, *Citizenship and the ethics of care: feminist considerations of justice and politics* (Routledge 1998).

⁶⁶ Director of Public Prosecutions, *Decision on Prosecution* (n15) paragraph 45(4).

⁶⁷ C O’Sullivan, ‘Mens rea motive and assisted suicide...’ (n58) 109.

⁶⁸ Director of Public Prosecutions, *Decision on Daniel James* (n51) paragraph 11.

⁶⁹ J Herring *Caring and the law* (Hart Publishing 2013).

option. These weaknesses suggest compassion is used as a definitional element of the defence to gloss over value that the DPP places on autonomy.

Concealing autonomy

In this section I argue that compassion is used as a mechanism by the DPP to conceal the fact that prosecutorial decisions concerning assisted dying are weighted heavily in favour of an autonomous decision. As Benders asks; ‘is freedom purely about autonomy or does it bind us together in a web of care, concern and obligation?’⁷⁰

Out of the six factors tending against prosecution, paragraph 45 (1), (4) and (5) are premised on the dying individual as having made an autonomous choice to commit suicide.⁷¹ As the evidential test for prosecution was certainly satisfied it almost appears that the public interest stage was formulated in a way that relates Mr James’s autonomy as a justification for why this appeared to be an “isolated” incident. Further to this, even though evidentiary criteria had been satisfied for prosecution the fact that capacity requirements were also satisfied overrides any form of public interest stage satisfaction. Throughout the DPP’s discussion of the public interest stage of the test, continual reference was made to Mr James’s capacity and ability to make an autonomous choice. The DPP described Daniel as a ‘fiercely independent young man with full capacity to make decisions about his medical treatment.’ Daniel was described as evaluating other care options, recognising how his current condition (and possible further suicide attempts) and travelling to Dignitas would affect his family. In comparison, the DPP’s justification for family assistance not being deemed as ‘ringleaders’ or using their ‘position of trust’ was underpinned by the fact that Mr James was deemed to have sufficient autonomy and therefore capacity to end his life with assistance. Biggs has argued that when applying the MCA to patients who lack capacity, taking account of the values and wishes of the

⁷⁰ S A Banderes, ‘Compassion and the Rule of Law’ (2017) *International Journal of Law in Context* 13 (2).

⁷¹ Director of Public Prosecution, *Policy for prosecutors* (n15) paragraph 45 (1), (4) and (5). Note that this is also mirrored in paragraph 45 (3) and (4).

individual mean that compassion will be at the very core of this analysis.⁷² Though the DPP guidelines serve the individual who has capacity, a similar analogy can be made: compassion can be used as a tool to understand the viewpoint of the individual who requires assistance. This forms part of our understanding of the role of autonomy in decision-making. This would then make the assister's reluctance and the attempt of dissuasion counter to the use of compassion as way to achieve respect for an autonomous decision on behalf of the individual who wishes to end their life.

Though the DPP guidelines provide 'limited evidence towards a compassionate basis for permissible legal change,'⁷³ if we are to take a compassionate understanding of autonomy as the basis for non-prosecution then certain evidential and safeguarding questions arise. As Biggs and the DPP note, it is difficult to ascertain evidence for capacity once the individual in question has died. Therefore, there is potential that there are insufficient safeguards to protect and support autonomous choice. In response to this, I argue that this highlights an opportunity to develop a more robust set of guidelines which explicitly outlines the reliance on satisfying autonomous choice rather than emphasising a narrow application of compassion.

Regulating (familial) assistance

The DPP guidelines do not characterise with clarity or certainty who can "legally" assist. For Coggon, this 'formal ambiguity' is valuable since constraint on prosecution is only attractive if the crime was always considered a public wrong (Coggon believes that assisted suicide is not always a public wrong).⁷⁴ The guidelines state that an assister is likely to be prosecuted if they were unknown to the victim, that the suspect was motivated by the prospect of gain from

⁷² H Biggs, 'From dispassionate law to compassionate outcomes in health-care law, or not' (2017) *International Journal of Law in Context* 13(2).

⁷³ *ibid* 182.

⁷⁴ J Coggon, 'Prosecution policy on encouraging and assisting suicide' (2010) *Journal of Medical Ethics* 36 (7)

the death of the victim, if they gave assistance to more than one victim and that the assister was paid by the victim or someone close to the victim or the assister.⁷⁵ This means that the assister who evades prosecution is likely to be an individual that falls into a neatly defined traditional and biogenetically linked familial paradigm. At first blush, the case of Daniel James and parental assistance appears as a paradigmatic example of this scenario and is arguably presented as this by the DPP. Yet with further investigation, specifically into the assistance by the family friend, what assistance means and whether a rights-claim could be developed is revealed. I argue that it is the lack of clarity concerning this type of assistance which Coggon has underestimated. Consequently, the status of the relational dynamic outside of these constructed familial norms remains ambiguous.

The DPP's decision on the Death of Daniel James focused much attention on the role of the Mr James's parents as opposed to the family friend. The DPP used the phrases 'ringleaders' and 'organisers'⁷⁶ to describe Mr James's parents. It was argued that Daniel's parents, despite taking a considerable organising role, were not ringleaders as such. This means that what relationship satisfies "known to the victim" is difficult to quantify. There are numerous ways this relationship could be defined. This relationship could be restricted to only biogenetically related ties. Alternatively only those who have a legally recognised relationship such as a marriage or civil partnership could be considered known to the victim. Despite a narrow construction of what would be considered a valid relationship these two examples highlight the different ways "known to the victim" could be defined. Further to this, outside of the biogenetically and legally recognised relationships are relationships which may be intimate but the individuals live apart. Indeed, it is questionable whether a "good friend" would also come within the definition of 'known to the victim.' What emerges from these possible

⁷⁵ Director of Public Prosecutions, Policy for prosecutors (n15) paragraph 43(11).

⁷⁶ Crown Prosecution Service, *Code for the Crown Prosecutors* (January 2013) <https://www.cps.gov.uk/publications/docs/code_2013_accessible_english.pdf> accessed 13 March 2017.

scenarios is that the definition of ‘known to the victim’ is broader than the one presented in the Decision on the Death of Daniel James. Thus the need for the DPP’s clarification of this is an important one, but it must also be recognised that clarification must come without normative definition. I argue that this could have been partially achieved if the DPP had accurately investigated the role of the family friend in the Daniel James’s case.

Instead, the DPP used a discussion of ‘organisers’ and ‘ringleaders’ to gloss over the fact that Mr James had been assisted by the family friend. Only four lines are given over to the role of the family friend before the DPP concluded that their involvement was less than Mr James’s parents.⁷⁷ Yet there was no analysis of the relationship of the family friend to Daniel. We do not know whether this friend was just a friend of Daniel James’s parents, how well he knew Daniel and how much encouragement he may or may not have provided. This is important because the death of Daniel James provided the DPP with an opportunity to make a distinction between different relational statuses and the type of assistance that would be “legitimate” in these instances yet they failed to do just this.

If the DPP made a distinction between the relational status of those who provided assistance there could have been scope to evaluate the relationship between each assister. I make this point because the level of assistance and motivation behind such assistance has the potential to be masked behind treating types of relational roles as the same. Thus each assister (for example, parents, siblings, and children) does not necessarily reflect the same relational and motivational dynamic in each scenario. It should not be presumed, as in the Decision on the Death of Daniel James, that Mr James’s parents’ role were equal in status and motivation in this context. Thus, within how we define who can “legally” assist, not only is the construction of relational status between assister and the individual who requires assistance

⁷⁷ Director of Public Prosecutions, *Decision on Daniel James* (n51) paragraph 27.

ambiguous but the relationship between assisters (if there is more than one present) also remains ambiguous.

A final point to be made in this section is the exclusion of individuals who do not have family or family who are unwilling to provide assistance. This was just the case in the appeal made by Martin in *Nicklinson*. Typically, individuals in this situation are likely to turn to a care professional to ask for assistance.

The role of the healthcare professional

The DPP's guidelines (influenced by Martin's appeal in *Nicklinson*) make clear that healthcare professionals and professional carers who have responsibility for the care of the dying individual are at risk of being prosecuted if they assist in the suicide of someone under their care.⁷⁸ This only applies where there is a relationship of care between the suspect and the victim.⁷⁹ Indeed the British Medical Association warned healthcare professionals to essentially "shut down" any questions regarding assisted dying. The effect of this is that healthcare professionals are warned to unrealistically disassociate themselves with the patient contemplating suicide. This may result in a messy and unpleasant death both for the dying individual and the assister. Not only does this discriminate against those who do not have access to familial assistance but presents assisted dying as a practice that should only be carried out in the private domain. The policy is 'designed to ensure that assistance in suicide remains an amateur activity carried out by inexperienced individuals.'⁸⁰

This section has discussed how the DPP's prosecutorial guidelines concerning assisted dying has embellished the Suicide Act. Indeed, the DPP's decision on the death by suicide of Mr James has created *de facto* decriminalisation of a specified scenario of assistance that is premised on an ambiguous definition of compassion. I have demonstrated that this definition

⁷⁸ Director of Public Prosecutions, Policy for prosecutors (n15) paragraph 43 (14).

⁷⁹ *ibid* paragraph 43 (14) footnote 1.

⁸⁰ P Hewitt, House of Commons Hansard HC Deb Vol 507 pc 54 col 403 10 March 2010. See further; P Lewis, 'Informal legal change on assisted suicide: The Policy for Prosecutors 2010.

is inadequate and in fact, individual autonomy within the bounds of a specified familial dynamic seems to govern the DPP's prosecutorial guidelines. By taking a care-based view to the DPP's guidelines it has been illustrated that the DPP fails to acknowledge the complexity of the assisted dying scenario. Further, what type of relationship is necessary between assister and the dying individual remains ambiguous. Though some argue that we should place trust in the Crown Prosecution Service and DPP in investigating cases of assisted dying,⁸¹ 'the opaque process of informal legal change by prosecutors'⁸² makes the current legal framework concerning assisted dying effectively untenable.

4. Summary

This chapter has analysed the most recent legislative attempts to legalise assisted dying. This analysis has critiqued the criteria established in the legislative Bills and concluded that terminal illness ignores those with long-term and degenerative conditions. Further, the use of suffering, although necessarily connected to a medical assessment reflects the subjective nature of quality of life arguments that are connected to the individual who requests assistance. This chapter also highlights the complexities of capacity and autonomy in regulating assisted dying. These complexities were demonstrated via a discussion of those living with dementia and the potential role advance directives for assistance to die could play. The next section focused on the influence of the DPP's guidelines. It was argued that the *de facto* decriminalisation resulted in a narrow and weak application of compassion which resulted in an ambiguous understanding of relational interaction. By using the Decision on Daniel James, I have argued that the type of assistance and relational dynamics should have been more thoroughly investigated. Instead, the DPP policy has shaped the current legal framework of assisted dying as the *de facto* legalisation of suicide tourism within a narrowly

⁸¹ J Coggon, 'Prosecutorial Policy on encouraging or assisting suicide – how much clearer could it be?' (2010) *Journal of Medical Ethics* 36 (7).

⁸²P Lewis, 'Informal legal change on assisted suicide: the policy for prosecutors' (2011) *Legal Studies* 31.

constructed ideal reflecting the typical focus of rights-based arguments. Any other type of assistance continues to remain legally ambiguous.

CHAPTER TWO: HOW CAN AN ETHIC OF CARE APPROACH HELP US BETTER
REGULATE ASSISTED DYING?

1. Introduction

In this chapter I will establish a care-based ethic which is tailored to the individual who requests assistance to end their life. In doing this, I will discuss each individual care actor that is connected to the individual who requests assistance. This will result in an evaluation of appropriate care-based theories required for their respective roles. The care actors involved in this scenario, and discussed in this chapter, include: the dying individual, family members or friends, the healthcare professional, the social care professional and state agencies. By discussing the role of each care actor, the limitations and advantages of care-based theories in the context of assisted dying will be evaluated. As such, this chapter will demonstrate that where requests for assistance to end life are made, care should be premised on positive private relational interaction and that this relation should be facilitated by both public and private systems of state support. To demonstrate this, in the following section I will briefly discuss the origins of a care ethic after establishing some definitional concerns concerning assisted dying.

2. Defining Assisted Dying

Vast contributions have been made to the suicide, euthanasia and assisted dying debates respectively. These contributions⁸³ have often focussed on the semantic and consent-based⁸⁴

⁸³ See further; P Lewis, *Assisted Dying and Legal Change* (OUP 2007); R Huxtable, *Euthanasia Ethics and the Law: From Conflict to compromise* (Routledge 2007); J Keown, *Euthanasia Examined: Ethical, Clinical and legal perspectives* (CUP 1995); H Biggs, *Euthanasia: Death with dignity and the law* (OUP 2001); S W Smith, *End of life decisions in medical care: principles and policies for regulation the dying process* (CUP 2012).

difficulties that arise when discussing assisted dying.⁸⁵ In this thesis, I adopt Otlowski's terminology.⁸⁶ Otlowski defines euthanasia as a clinical situation where a healthcare professional assists a terminal or incurable patient to die *or* the intentional killing, often by a family member or friend of the dying individual for reasons of pity or mercy for the suffering person.⁸⁷ With regard to the type of issues raised in this thesis I distinguish between passive euthanasia and active euthanasia. Active euthanasia is defined as a deliberate act to end an incurable or terminal patient's life and bring about the patient's death. Passive euthanasia is defined as the deliberate withholding or withdrawing of treatment; the object being to hasten the patient's death.⁸⁸ For the purposes of this chapter, "assisted dying" refers to the situation where one or more people help another person to end their life.⁸⁹

3. What is a care ethic?

The term 'care ethic' originally derived from Gilligan's critique of Kohlberg's theory of moral development.⁹⁰ Kohlberg argued that the success in solving moral dilemmas was determined using abstract duties and principles. These principles, often referred to as justice-based frameworks, were given a privileged status in moral decision making.⁹¹ Kohlberg went on to argue that females and males viewed moral dilemmas differently; males chose to use justice-based frameworks whereas females chose a contextualised approach to moral decision making. In turn, Gilligan argued that recognising interdependence in moral dilemmas and

⁸⁴ See further, G Laurie *et al*, *Mason and McCall Smith's Law and Medical Ethics* (10th edn, OUP 2016) 612.

⁸⁵ Where appropriate, this will be discussed in the further chapters.

⁸⁶ M Otlowski, *Voluntary Euthanasia and the Common Law* (n22)

⁸⁷ *ibid.*

⁸⁸ *ibid.*

⁸⁹ Where assisted dying practices require further definition, this will be stated.

⁹⁰ C Gilligan, *In a different voice: psychological theory and women's development* (HUP, 1982).

⁹¹ For a further description of Kohlberg's theory see further; L Kohlberg, *The philosophy of moral development* (Harper & Row 1981) 17-19, 408-412; L Kohlberg and R Kramer, 'Continuities and discontinuities in childhood and adult moral development' (1969) *Human Development* 93-120.

then using empathy and compassion to solve such dilemmas served as an alternative understanding of moral development.⁹² Thus Gilligan established a care-ethic which relies on a bond of interdependence between two individuals who act responsively towards others to sustain caring practices.⁹³ Gilligan then argued that removal of emotions from moral decision-making restricted the ability for the individual to record experience in order to navigate the social world successfully.⁹⁴ This was demonstrated by Gilligan's argument that the paradigmatic voice in judicial reasoning, such as in *Roe v Wade*, was of Kantian liberal autonomy and natural rights.⁹⁵ Care ethics has therefore been placed in opposition to the traditional moral position that reflects a Kantian ethic.⁹⁶ Contributions to the care ethic literature has grown widely since Gilligan's construction of a care-based theory of morality, including a substantial critique of Gilligan's original conception. Because of Gilligan's connection to familial care I will return to a critique of Gilligan's care-based ethic in the discussion of family in section five. First though, in the next section I will discuss the role of care in application to the dying individual.

4. The Dying Individual

At the centre of the assisted dying debate is the individual who requests assistance to end their life. Typically, the dying individual has a degenerative or terminal illness which results in a continuing loss of quality of life. However, it is important to note that the current UK case law has not included appeals from those who are terminally ill, but rather those with a degenerative illness. Indeed, Lord Falconer's Assisted Dying Bill⁹⁷ restricted assisted dying to those with a terminal illness and six months to live. I make this point because the type of

⁹² C Gilligan, *In a different voice* (n86).

⁹³ *ibid.*

⁹⁴ C Gilligan, 'Hearing the difference: Theorising connection' (1995) *Hypatia* 10 (2).

⁹⁵ *ibid.*

⁹⁶ I Kant, *The critique of practical reason* (Dover Publications 2004).

⁹⁷ Assisted Dying Bill [No 2] HL.

care and experience (especially with regards to longevity) could be different between the two diagnoses. Therefore, when discussing the dying individual, one should not presume that their illness is terminal but rather it could also be degenerative over a long period. The type of care that the dying individual therefore requires is primarily physical and emotional. In the instance of a degenerative illness, often there is an increasing need for invasive care as life continues. It is also notable that the dying individual may also require financial support. Apart from being the recipient of care, the dying individual's role is that of the decision-maker for how their life will proceed and what type of care they wish to receive. The issues concerning these decisions involve a broad range of factors. These include, but are not limited to when, where and how they may want to proceed with their life; financial costs of their situation, and the impact on the relationships they have with others. The answers to these factors are fact-sensitive and may result in different outcomes, including a want to end their life. This then raises the question of how a care ethic can assist individual decision-making.

How can a care ethic support individual decision-making?

I argue that a process-based view of autonomy can support the decision-making process of the individual who wishes to end their life. Process-based autonomy is a structural or procedural way of appropriate decision making, most commonly associated with Harry Frankfurt and Ronald Dworkin respectively.⁹⁸ This differs from traditional perspectives which define autonomy as the ability for self-determination which is free from external influence.⁹⁹ The type of procedural autonomy I wish to promote in this chapter is care-based

⁹⁸ H Frankfurt, *On Bullshit* (Princeton University Press 2005); R Dworkin, *Justice for Hedgehogs* (Belknap Press, 2009).

⁹⁹ I Kant, *The critique of practical reason* (Dover Publications 2004).

relational autonomy derived from Meyer¹⁰⁰ and Friedman's¹⁰¹ respective theories. I have chosen their versions because of the emphasis on the contextualisation of factors in the decision-making process.¹⁰² Because the individual's decision to request assistance is inextricably linked to individual experience, process-based autonomy can form part of an appropriate care model to evaluate decision-making.

Both Meyer and Friedman's contribution to process-based autonomy literature involve a critical reflection, both cognitive and emotional, of the historical basis of desires and preferences. Meyer argues that decision making can be both a localised and immediate decision but also episodic, referring to larger life goals and plans.¹⁰³ For Friedman, the outcome of the decision-making process results in absolute support for preferences or an absolute endorsement of preferences.¹⁰⁴ The benefits of Friedman's approach is that decision-making is not just concerned with negative liberty of the freedom from external influence, which represents the typical autonomous paradigm, but the ability to consider a full spectrum of moral issues bearing upon the individual who requests assistance.

When applied to the decisions the dying individual must make, a categorisation of immediate and episodic decisions is unhelpful. Planning for a life with a degenerative or terminal illness will, in most instances, involve decisions about the stages of experience with regards to quality of life. Though autonomous immediate decisions will be made day-to-day, the desire to end one's own life is a decision that should be premised on an episodic consideration of future life plans and goals. This is because the consequence of such a decision is death, and

¹⁰⁰ D Meyer, 'Intersectional identity and the authentic self. Opposites Attract!' in Mackenzie and Stoljar (eds), *Relational autonomy: Feminist perspectives on autonomy, agency and the social self* (OUP 2000).

¹⁰¹ M Friedman, *Autonomy, Gender, Politics* (OUP 2003).

¹⁰² See further; Mackenzie and Stoljar, 'Introduction: Refiguring Autonomy' in Macenzie and Stoljar (eds) *Relational Autonomy* (n98).

¹⁰³ *ibid.*

¹⁰⁴ *ibid.*

so does not fall into the same category of consequences that episodic or day-to-day decision making has.

Notably though, the support/endorsement of preferences which Friedman advocates prompts an important discussion surrounding autonomy and assisted dying. There may be an expectation that the dying individual, if choosing to end their life, must have to absolutely endorse¹⁰⁵ such a preference; that life and death are two opposing options, with the individual choosing between them. However, the use of ‘absolute support’ for preferences draws a more detailed understanding of autonomy and how the dying individual makes the choice about their future life plans. This is because ‘support for preferences’ recalibrates the decision surrounding choosing to die. It presents the practicalities of the dying individual’s scenario; that choosing to end one’s life because of a degenerative or terminal illness is a preference over living with the symptoms of their illness. It is not an isolated decision about the value of death itself. If the dying individual is forced to make decision to end their life premised on absolute support, there is a potential that we make a value-judgment on the value of life as opposed to death without considering the context and associated individual experience that this decision lies within. By recognising that decision-making is part of an evolving collection of attributes, a more comprehensive evaluation of the individual’s preferences can be considered. Though a subtle distinction, it is an important one – it ensures that the decision to end one’s life is grounded in the realities of experience.

An issue is raised, however, when care-based procedural autonomy is applied to the dying individual who lacks capacity to make decisions. Typically, these patients will be in a persistent vegetative or minimally conscious state. In this scenario, the individual decision-maker lacks the ability to communicate their wishes. In such scenarios, a decision is made after an evaluation of what is in the best interests of the dying individual. I argue that the

¹⁰⁵ M Friedman, *Autonomy, Gender, Politics* (n99).

same types of factors involved in Meyer and Friedman’s respective theories can be included in the analysis of the dying individual’s choice. However, I also argue that the use of these factors are more applicable to a substituted decision, rather than deciding what is in the individual’s best interest. This is because there is a disparity between what might be objectively “good” compared to the subjectivity of the individual’s choice, if they had the capacity to make it. A care-based ethic should prioritise an investigation into autonomous choice rather than best interests.

Thus far my discussion of procedural autonomy has been premised on an assumption that all relationships are positive. It presumes that caring relationships do not encourage pressure on the individual to end their life and that the dying individual has (or had) sufficient access to all available information about their condition and attached experience. Given this, as both Friedman and Meyer note respectively, the state must play a role in supporting decision-making and protecting individuals from the results of decisions made by others. This will be discussed in an evaluation of the state’s role in section seven.

I argue that a process-based understanding of relational autonomy recognises the realities of individual decision-making. This is because it grounds the dying individual’s decision in ending their life. The following section then, will discuss the practice of care for the individual who requests assistance from the perspective of family and friends.

5. “Family”

In immediate proximity to the dying individual are the family and friends who have a close personal relationship with the dying individual. The type of care provided is typically physical care labour, emotional support but can also include financial support. The type of care often associated with this scenario is premised on the maternal paradigm. In *Caring*,¹⁰⁶

¹⁰⁶ N Noddings, *Caring: A relational approach to ethics and moral education* (2nd edn, Univeristy of California Press, 2013) 42.

Noddings states that care is the active preservation of a connection with the one that is cared for, using the mother-child paradigm as a dominant example. Individuals are perceived by Noddings as ‘sensitive receptive and responsible agents.’¹⁰⁷ Just as Gilligan¹⁰⁸ and Ruddick¹⁰⁹ argue, Noddings premises care as something that is natural and inherently known by mothers. The practice of caring then, is an ‘engrossment’ in the one who is cared for and therefore requires the care provider to ignore their own personal motivating values in favour of the care receiver.¹¹⁰ Noddings then categorises the practice of care through the use of relational circles. In the inner circle are family and friends who care because they love, outside that circle, the individual cares because of their situational or professional role, such as a teacher. Outside of this dynamic are strangers. Noddings argues that we care for strangers because they have the potential of coming within the two inner circles and are therefore owed some form of care-based recognition.¹¹¹ What can be taken from the maternal paradigm and Noddings’s care ethic is positive and meaningful relational interaction. I argue that the care provided by family and friends is reliant on the positive and meaningful relational interaction that Noddings describes. However, positive relational interaction cannot be read in isolation and Noddings, together with her fellow maternal care theorists are susceptible to critique.

Firstly then, a maternal model of a care-based ethic encourages a gendered account of what it means to care. The use of the maternal paradigm in both Noddings and Ruddick’s work suggests that care is only applicable to women in the nuclear family and therefore care is somehow only understood and successfully practiced by women. This encourages the belief that women have a separate female morality. This is reflected in Gilligan’s own research,

¹⁰⁷ *ibid.*

¹⁰⁸ C Gilligan, *A different voice* (n56).

¹⁰⁹ S Ruddick, *Maternal Thinking: Towards a politics of peace* (2nd edn, Beacon Press, 1995).

¹¹⁰ N Noddings, *Caring* (n102).

¹¹¹ *ibid.*

which relies on a distinct difference between male and female psychological development and the social construction and experience of gender roles. As Green and Maccoby suggest, Gilligan's sample size and characteristics of participants in Gilligan's justificatory study are inadequate for drawing conclusions. Males and females do actually use care and justice-based frameworks equally.¹¹² Consequently there is no necessary reason to presume that moral reasoning between males and females is based on inherent biological differences. In conceding this, Gilligan maintains that female experience is still important as it provides 'activities that constitute care.'¹¹³ Yet as Brabeck argues, in an attempt to suggest a different approach to moral decision making, Gilligan defines the traditional maternal paradigm as the activity that constitutes care, as a moral ideal.¹¹⁴ By using maternal care paradigms, care is considered an inherent female behaviour, not one that is learnt, and only applicable in the nuclear family. Gilligan's contribution should not be used as a guiding concept for a modern-day care ethics. Indeed, given it is clear that gender does not impact on care, 'the importance of the ethics of care, and its transformatory potential, does not, and indeed must not, rest on the association with women.'¹¹⁵

Secondly, an important point to raise in response to the individual who requests assistance, is the trend for maternal care theorists to romanticise the practice of care. Noddings perceives care to be a practice which results in a positive experience for both parties. But in reality, care can include negative emotions, it can be messy and it can be flawed.¹¹⁶ If positive experiences of care are seen as a normative ideal, we stigmatise those whose caring experiences do not

¹¹² C Green and E Maccoby, 'How different is the "different voice" (1986) *Signs* 11 (2). See further, L J Walker, 'Sex differences in the development of moral reasoning: A critical review' (1984) *Child Development* 53 (3).

¹¹³ C Gilligan, 'A Reply' (1986) *Signs* 11 (2).

¹¹⁴ M Brabeck, 'Moral judgment: Theory and research on differences between males and females' (1983) *Developmental Review* (3).

¹¹⁵ F Robinson, *Globalising care: Ethics, feminist theory and international relations* (Westview 1999) 23.

¹¹⁶ D Cooper, 'Caring for sex and the power of attentive action: Governance, drama and conflict in building a queer feminist bathhouse' (2009) *Signs* 35.

realise this ideal. Care should be viewed as a practice which is learnt, inclusive of both negative and positive emotions. Moreover, by moving away from the maternal paradigm of care, but still recognising positive relational interaction, how we care can be explored. As Cooper notes, caring does not have to include a deep and sustained hands-on practice, like that of child rearing. Care can include monetary support, the organisation of care labour itself plus momentary and “trivial” acts of care. For the individual who requests assistance then, the plurality of caring practices, not just the physical care labour that family and friends provide, is an important contribution to a care ethic. Though broad in her definition, Tronto’s care perspective illustrates just this; ‘a species of activity that includes everything we do to maintain, contain and repair our ‘world’ so that we can live in it as well as possible. That world includes our bodies, ourselves, and our environment.’¹¹⁷ By recognising the scope of caring practices we can realise the different dimensions of care that can aid positive relational interaction. In realising the positive and negative experiences of familial care, the state can be encouraged to facilitate positive relationships by providing both public and private systems of support.

At this juncture, it is appropriate to define what family and friends mean to a gender-neutral care-ethic. This definition has significance not only for the relationship of care in the private domain but also how this affects the state’s role in the facilitation of care in the public domain. Gilligan argues that relationships are a natural part of our existence and therefore necessary for the survival of society.¹¹⁸ Similarly, Friedman has argued that the reason we have certain obligations to others is because of relational interaction.¹¹⁹ Yet neither theorist justify why relationships should take a central role in moral theorising. As a naturalistic

¹¹⁷ J Tronto, *Moral boundaries: A political argument for an ethic of care* (Routledge 1993) 134-136.

¹¹⁸ C Gilligan, ‘Moral injury and the ethic of care: Reframing the conversation about differences’ (2014) *Journal of Social Philosophy* 45 (1).

¹¹⁹ M Friedman, ‘Care and context in moral reasoning’ in Kittay *et al* (eds) *Women and Moral Theory* (Rowman and Littlefield 1987).

fallacy, they are forced to define relationships from a “natural” perspective. This perspective prescribes that care is only pertinent to the nuclear and biogenetically linked familial paradigm.

However, I argue that care exists in a plurality of relationships, without being dependent on traditional nurturing roles and biogenetic ties. In her discussion of the familial institution, Fineman¹²⁰ has not defined what constitutes “the family.” Perhaps her lack of definition is exactly the point, that it should not be defined for fear of constructing socially acceptable roles. However, in order to differentiate between the type of care required in the private domain and the type of care required in the public domain I will discuss what positive relational interaction within the setting of “family” means.

As established above, positive relational interaction does not have to be premised on biogenetic ties. As Barnes notes, friendship can offer informal and reciprocal models of care.¹²¹ Indeed, relationships of care have typically been seen as an interaction that concerns only two parties, a perception which is evident in the work of maternal theorists discussed. However, relationships can include multiple parties, such as collective communities and multigenerational households.¹²² Interestingly, Barnes notes that care may arise from membership of groups, where the group was not formed for the purpose of caring.¹²³ I argue that Barnes’s argument illustrates that care as both a practice and attitude is a continually evolving concept which is responsive to multiple environments. Thus, positive relational interaction does not just exist in the traditional private domain.

¹²⁰ M A Fineman, ‘The Vulnerable Subject: Anchoring Equality in the Human Condition’ (2008) *Yale Journal of Law & Feminism* 20 (1).

¹²¹ M Barnes, *Care in everyday life: An ethic of care in practice* (Policy Press 2012).

¹²² *ibid.*

¹²³ *ibid.*

When does positive relational interaction with another (or others) become defined as familial care?

I agree that “family” is chosen and premised on sentiment, emotion and material aid.¹²⁴ When family is discussed within a care-based ethic then it should be presumed to mean the particular type of family we choose and are free to be ‘different in kind and composition.’¹²⁵

For the individual who requests assistance, it should not be presumed that those offering care are biogenetically linked or are part of traditional nuclear familial paradigms.

Wolf argues that caring for those whom we have a personal kinship with above those who are strangers is morally justifiable, as relationships ‘unquestionably rank among the greatest goods of life’.¹²⁶ Owing a heightened level of caring practice with whom the care agent is in a relationship forms part of that positive relational experience. Moreover, by caring for those who are in spatial proximity to us allows for the ability to continually exercise the practice of care. However, Wolf’s moderate impartialism requires that the care agent (the familial member in this instance) also recognises the equal respect owed to all members of that community. This could serve as an indication that a care ethic (broader than a discussion of assisted dying) requires a relational framework that prioritises caring practices between different relationships.

This section has argued that in response to the individual who requests assistance to die the type of appropriate care which is required in the familial domain is a positive relational interaction, the very core of Noddings’s work. However, the type of care provided should not be in a maternal structure. Instead, familial care should be premised on the realities of the practice of care; that the result is often both positive and negative, while such practice may include a plurality of acts which are not necessarily sustained and meaningful. In addition,

¹²⁴ See further K Weston, *Families we choose: Lesbians, gays, kinship*. (Columbia University Press, 1991).

¹²⁵ *ibid* 110.

¹²⁶ S Wolf, ‘Morality and partiality’ (1982) *Philosophical Perspectives*.

though I have emphasised care in the private domain, this caring relationship should be premised on the choice of a particular relationship based on sentiment, emotion and material aid. I will draw further on this distinction when discussing the role of the healthcare professional in response to requests for assistance in the following section.

6. The Healthcare Professional

The healthcare professional is an individual that is professionally regulated who provides medical or health-related care. Typically, for the individual who requires assistance to end their life, healthcare will be provided by an inter-disciplinary team which include doctors, nurses, psychiatrists and occupational therapists. However, for the purpose of this chapter, the role of the doctor and nurse as healthcare professionals will be discussed. The type of care that the healthcare professional provides in this instance is one of medical diagnosis and management of symptoms as well as clinical responsibility for the maintenance of health and wellbeing of the dying individual. Inclusive of the clinical skill required to deal with the complex care needs of the patient, healthcare professionals also have a responsibility to approach their professional-patient relationship with sensitivity and understanding of the individual's circumstances. Indeed, in recent years emphasis has been placed on ensuring a successful professional-patient relationship.¹²⁷ Therefore, in consideration of the individual who requests assistance, the type of care and how this is framed in the professional-patient relationship requires analysis.

Given that the healthcare professional is regulated by both professional and legal standards, I argue that the healthcare professional's role should be premised on Tronto's¹²⁸ principled and consequentialist approach to care. As stated earlier in section four, Tronto defines care as, a 'species of activity that includes everything we do to maintain, contain and repair our 'world'

¹²⁷ GMC, Good Medical Practice (GMC 2013) para 49 < http://www.gmc-uk.org/uidance/good_medical_practice/partnerships.asp> accessed 31 January 2017.

¹²⁸ J Tronto, *Moral Boundaries* (n115).

so that we can live in it as well as possible. That world includes our bodies, ourselves and our environment.¹²⁹ Though I recognise the reason Tronto uses this definition is to broaden the scope of care from the maternal and private paradigm, for the purpose of the healthcare professional's role and the individual who requests assistance, the scope of caring activity needs to be constrained. The reason for this is (a) the practical ability for the healthcare professional to adequately care for the individual and (b) the necessity of the boundary between public and private types of care and relationships. Where Tronto's principled approach is applied, it is only concerned with the application of clinical skill, communication of clinical diagnosis and possible treatment plans and supporting patients with regards to their healthcare choices.

Based on this I will apply Tronto's care ethic. Tronto's care ethic categorises care fundamentally as a practice which is open to cultural variation not restricted by normative boundaries.¹³⁰ However Tronto does offer four principles which act as dispositions. These principles are attentiveness, responsibility, responsiveness and competency. Attentiveness requires the individual to recognise the need in others to provide an appropriate response. This ultimately results in a propensity to become aware of need. This is similar to Tronto's principle of responsibility which distinguishes responsibility from societal constructions of obligation. Responsibility is not defined by structures of social expectation but rather a flexible undertaking of caring roles. Competency requires the care giver to provide adequate care. Finally, responsiveness on behalf of the individual who is cared for reflects care itself: responsiveness expresses the vulnerability of the one who is cared for. This principled and consequentialist approach distances itself from the contextualised care that is endorsed by maternal care theorists as discussed in the previous section.

¹²⁹ *ibid* 134-136.

¹³⁰ *ibid*.

Tronto's understanding of responsiveness is modelled on the concept of vulnerability. Given Tronto's politically orientated care-based framework, I will argue that vulnerability can be defined considering Fineman's vulnerability thesis. Fineman describes vulnerability as a 'present potential for each of us to become dependent based upon our persistent susceptibility to misfortune and catastrophe.'¹³¹ Vulnerability can either be biological or as a result of negative societal structures and environment the individual experiences.¹³² Under Tronto's framework, the healthcare professional must recognise the inherent vulnerabilities that the individual is experiencing. I question whether this is the same as Tronto's principle of attentiveness. If attentiveness is the recognition of the individual's needs, then are these needs not encompassed by the concept of vulnerability? Though I recognise that Tronto's purpose was to raise care to a political platform, when applied to the healthcare professional's role – responsiveness and attentiveness encompass the same concept, namely to recognise the need of the patient.

However, the concept of responsiveness is still an important component in the type of care that the healthcare professional owes to the patient. Responsiveness ensures an active recognition of the patient rather than their wider politico-socio impact that is described by Tronto. Despite the reliance on gendered norms and maternal paradigms of care, Noddings's description of responsiveness is a useful contribution to the discussion of the healthcare professional's framework for care. Under Noddings's account responsiveness is a reaction on behalf of the care receiver to the care that is given.¹³³ For example, for the individual who requires assistance to die, specifically with regard to patients in a persistent vegetative state, this response is inclusive of a basic embodied response. For example, the patient responds to being kept clean by not smelling. However, also pertinent to the individual who requests

¹³¹ M A Fineman, 'The Vulnerable Subject' (n118).

¹³² M A Fineman, *The Autonomy Myth: A Theory of Dependency* (The New Press 2004).

¹³³ N Noddings, *Caring* (n102).

assistance is the type of response required from the patient. Under Noddings's theory (as discussed in section four) the concept of responsiveness portrays caring practices which are positive or are implicitly conducive of the desired response of the care provider. For example, a healthcare professional may advise a patient to continue treatment and explains that death may be a result of doing so. Yet the patient chooses not to take the medication. Just because the patient has not adhered to the advice of the healthcare provider does not mean they have not responded, for in acting on such advice a response has been achieved. Therefore, responsiveness is not a recognition of vulnerability. Instead responsiveness is a *literal* response to care provided and not necessarily one that relies on a perceived positive response to the care provided by the healthcare professional.

Competency is as an integral requirement of the care ethic that is suggested for the healthcare professional's role. The provision of competency recognises the obligation to ensure care is provided at an appropriate standard. However, for the individual who requires assistance, such as patients with degenerative or terminal illness, competency should not be defined as "curing." Competency should instead be understood as caring for the wellbeing of the individual patient. This may include the alleviation of symptoms, offering alternative treatment plans and importantly recognising the patient's choice to die by either refusal of treatment or a positive action to end life. Defining competency as recognising patient choice means that there needs to be a discussion about whether that choice conflicts with societal concerns. Therefore, the following paragraphs will discuss the political role of care while also looking at the positioning of the healthcare provider in the socio-political landscape.

What type of societal model of care is appropriate?

I suggest that a care ethic should be underpinned by communitarianism and that Tronto's definition of care can be viewed as an appropriate model.

Communitarianism is defined as a normative theory that places emphasis on the self-governance of communities where the individual has responsibility to the community.¹³⁴ The traditional liberal view of communitarianism is defined as the capacity for rational self-legislation which results in self-determined and self-governing choices. This approach prioritises normative identity constructs, like that of the maternal and nuclear familial paradigm. Instead I argue that the values endorsed by a communitarian care ethic must be ones which place equality of kinship, identity and care at its core. There should not be a distinction between identities based on constructions such as gender, sexual orientation race or class. This requires an explicit recognition of public interaction. I define public interaction as individual and state responsibility of involvement in the facilitation of and discussion of care in the context of community responsibility. How this achieved will be discussed in application to the role of the healthcare professional.

Having already established that healthcare is premised on “care not cure,” and given that doctors can end a patient’s life, they can be considered as active participants in assisting an individual to die. Yet as Sherwin argues, often healthcare theorists have focussed on specific relationships in the healthcare setting, rather than taking a view of the wider structural aspects of care.¹³⁵

In the current healthcare setting, healthcare professionals must respect a patient’s refusal of treatment even if this refusal results in the death of the patient.¹³⁶ Moreover, it is legal for a doctor to withdraw treatment from patients who lack capacity (typically because they are in a persistent vegetative state or minimally conscious state.)¹³⁷ These two factual scenarios highlight the type of role the healthcare professional plays within the context of assisted

¹³⁴ Aristotle, *Nicomachean Ethics*, Books I and II.

¹³⁵ S Sherwin, *No longer patient: Feminist ethics and health care* (Temple University Press 1992).

¹³⁶ See further; *Re B (Consent to treatment: Capacity)* FD 22 Mar 2002.

¹³⁷ see further; *Airedale N.H.S. Trust v Bland* [1993] A.C. 789.

dying. In both scenarios, the healthcare professional participates in passive euthanasia by withholding and withdrawing treatment. Though in these scenarios the healthcare professional is not administering a lethal dose of medication and not participating in active euthanasia, healthcare professionals are inextricably linked to the death of the individual patient.

If the type of care appropriate to the healthcare professional in this scenario is to ensure that the dying individual should have positive relationships in the private domain, the healthcare professional could have a role to play in ensuring this, which is inclusive of taking part in assisting the death of the individual. As the GMC states, 'good doctors make the care of their patients their first concern.'¹³⁸

However, I also argue that healthcare professionals have a right to object to providing care based on a conflict with their own beliefs. Typically, for the individual who requests such assistance, there are usually other healthcare professionals that care can be handed over to if this is the case. However, where this is not the case, I argue that the care ethic suggested in this chapter does not include the scope for conscientious objection. This is because this is premised on a consequence of good care, if objection breaks this model, competent care has not been achieved.

This section has discussed the role of the healthcare professional in the context of the treatment and care they provide. I have argued that Tronto's principled and consequentialist approach to care which recognises the individual need of the patient is the most appropriate framework for care. This has included an analysis of the relationship between the healthcare professional and their status in society and how conscientious objection is incompatible with the type of care suggested in this section. In building on the type of care pertinent to

¹³⁸ GMC, Good Medical Practice (GMC 2013) (n125).

professional bodies, the following section will discuss the role of the social care professional in connection to the individual who requests assistance to die.

7. The Social Care Professional

The social care professional is a person employed to arrange or perform personal care or social support for the dying individual. For the individual who requires assistance, the type of social care required will vary depending on the needs of the individual. Care is typically provided by social workers, occupational therapists, social group coordinators and personal care staff. For this section I will focus on the role of the personal carer. This illustrates the difference between types of professional social care and the provision of care in the private domain. The type of care that the social care professional provides is typically physical care labour. Their role does require professional skill (though currently not professionally regulated) but not clinical or medical skill. Fundamentally, the day-to-day physical care labour they provide replaces the physical care labour that would typically be provided by a family member in the private domain. The social care professional provides care that is akin to the care expected by the familial role. This provides an interesting dynamic for the appropriate type of care expected; on one hand, there is an expectation of a professional type of care, on the other hand, they are emulating the intimacy of care that the familial care provider typically delivers.

I argue that Tronto's principled approach is also appropriate to the social care professional's role in response to the individual who requests assistance. We know that the physical care labour that the individual requires must be competently performed and that the social care professional must also be attentive to the needs of the individual. Typically, the social care professional will enter the individual's home or personal life that the healthcare professional does not necessarily encounter (although it is appreciated that community health services do also do this – and this critique is perhaps pertinent to those healthcare professionals also).

I argue that in the context of the social care professional's caring role, the principle of responsibility should be given primacy over the other principles suggested by Tronto. Though it is noted that the social care professional's relationship with the dying individual is limited by professional conduct, I argue that the type of relationship the social care professional has with the individual is more flexible. This is due to care being provided in the private home of the individual more so than healthcare professionals in the clinical setting. By assigning flexible relational conduct with the dying individual and informal or familial carer, the social care professional can provide competent care.

Owing to the practice of care usually being provided in the home, the type of relationship between the social care professional and the individual is an important dynamic of the care provided. In this instance, responsibility (the relational principle of Tronto's care ethic) dictates and influences how the other principles should be applied.

Akin to the discussion of the principled approach applied to the role of the healthcare professional, the application of a care ethic raises the issue of whether an emotional response to care forms part of the social care professional's role. This argument is raised because the social care professional treads between boundaries of a professional care-provider and private familial care provision; they replace the private care labour that was once carried out by familial members.

A genuine and legitimate feeling of wanting to care for the individual draws parallels with Hamington's embodied response to care.¹³⁹ Hamington argues that knowledge of the care-receiver's need is a visceral response to what the body exhibits. I argue that an intuitive response to a need does not mean that the care agent chooses to care, and if they do, that the care is performed competently. As a King's Fund and Nuffield Trust Report *Social care for older people: Home truths* aptly illustrates, personal care is '(...) an incredibly difficult job,

¹³⁹ M Hamington, *Embodied care: Jane Addams, Maurice Merleau-Ponty and Feminist Ethics* (University Illinois Press 2004).

difficult profession, which doesn't pay very well, where you're being asked to do more and more on less ratios that will become less appealing.'¹⁴⁰ In this scenario, as a description of Hammington's theory illustrates, the social care professional must want to care. However, an alternative to Hammington's arguments can be suggested. If paid care labour was given greater social and financial value, it is likely that we would encourage competent care – even if such care professionals did not want to care.

This section has argued that the role of the social care professional should be premised on the principled approach that Tronto advocates previously discussed in section six. Importantly, the practice of familial-type care in the private domain must be socially and financially valued, and where this is not the case the social care professional must want to authentically care. The next section will discuss how the different types of care discussed in the above sections are facilitated by the state.

8. Government Agencies

The state dictates the status of care as a practice both in the public and private domains and the interrelationship between these two spheres. The type of government agencies involved in the care of individuals who request assistance to die will vary from the provision of health and social care professionals discussed above, to financial support such as personal care budgets. This will also extend to the police service in investigating possible assistance to commit suicide and the Crown Prosecution Service's role in publishing prosecutorial guidelines.

¹⁴⁰ King's Fund, 'The Spending Review: what does it mean for health and social care?'

<[https://www.kingsfund.org.uk/sites/files/kf/field/field_publication_file/Impact of the 2015 Spending Review on health and social care %28joint submission%29.pdf](https://www.kingsfund.org.uk/sites/files/kf/field/field_publication_file/Impact%20of%20the%202015%20Spending%20Review%20on%20health%20and%20social%20care%20joint%20submission.pdf)>accessed 23 December 2016.

I argue that the type of care that is appropriate to government agencies is one that is premised on various factors. These include but are not limited to; financial considerations, political ideologies, material resources and workforce resources. Therefore, a care ethic that can compete as a political force is required. The following paragraphs will discuss why the state and government agencies should facilitate a private positive relationship by providing both public and private systems of support.

In *Caring and the Law*, Herring discusses why the practice of care matters to the state.¹⁴¹ Possible arguments that are considered include economic reasons, social fairness, gender equality and claims from morality. Though valid, I will not discuss an argument from the base of gender equality, since the thesis here seeks to move beyond the maternal and gendered paradigm of a care-based ethic.

Care justified on a cost-benefit analysis results in the provision of care via payment or state financial support (at a minimal level) and is suggested to be economically beneficial to society. It is argued that seeing care as an economic commodity, with state support for care in the private domain provides significant state financial savings. For example, Care UK argue that the value of unpaid care provided by informal carers in the UK totals £132 billion.¹⁴² Yet, it is estimated that by 2019/20 there will be a funding gap of £2 billion, which in reality means spending on social care of GDP will be at 0.9%. It is likely that carers will continue to provide informal care without the state financing the real value of the care provided.

Despite the political arguments that are invoked by such statistics, it is evident that state support for a “minimum” level of care which encourages unpaid carers to continue caring is a cheaper alternative than funding all types of care that unpaid carers provide. It is, however, a

¹⁴¹ J Herring *Caring and the law* (n69).

¹⁴² King’s Fund ‘The Spending Review: what does it mean for health and social care?’ <[https://www.kingsfund.org.uk/sites/files/kf/field/publication_file/Impact of the 2015 Spending Review on health and social care %28joint submission%29.pdf](https://www.kingsfund.org.uk/sites/files/kf/field/publication_file/Impact%20of%20the%202015%20Spending%20Review%20on%20health%20and%20social%20care%20%28joint%20submission%29.pdf)> accessed 23 December 2016.

dangerous proposition that care is justified in purely monetary terms. This is because this model of fiscal efficiency means that the relational aspect of care is not valued. This has negative ramifications for the positive private relational interaction between the familial care provider and the individual who requests assistance. If spending on social care is likely to decrease, and informal care provision will make up this gap, a reasonable inference can be made that the increased pressure to care without state support will affect the relationship between the familial care provider and the dying individual. This relationship may not be positive but negative.

Further to this, state funding of care poses the risk that the state has ultimate control for regulating care. At times this may mean removing care from the private domain, where qualitative output is better but fiscal efficiency is worse (and vice-versa). By supporting care provided by a third party, whom one can presume is paid (either formally by the state or through payment by the dying individual) raises the issue of care as a commodity. I argue that this is an important issue to raise within this chapter. A replacement of care which once predominantly existed in the private sphere to a commercial model changes the expected practices of care by professional care providers which then could have an effect on the type of relational dynamics that exist in the private domain.

Alongside the commercialisation of care in the public domain there are arguments to suggest that paid care enables relational boundaries in the private sphere and allows for competent and successful provision of care.¹⁴³ Indeed, Fineman has argued that payment for care allows care to be valued.¹⁴⁴ However Herring has argued that care work can often be under-paid and as such, de-valued. In addition, care may have a market value but can also have a non-monetary value attached to it. Thus Herring argues that payment for care should be viewed as

¹⁴³ V Held, 'Care and the Extension of Markets' (2002) 17 *Hypatia* 19.

¹⁴⁴ M Fineman 'Contract and Care' (2001) 76 *Chicago-Kent Law Review* 140.

enabling care rather than valuing it.¹⁴⁵ Though in principle Herring makes a valid point, I argue that in reality, monetary value has a far greater influence on the value of care objects and services than posited in his argument. Indeed, I argue that this has an even greater impact when considered in light of policies such as personal care budgets (where the individual is given a sum of money by the state to pay for care services in the way they deem appropriate). In turn, I argue that where care is discussed, market values are not applied to the practice of care or necessary caring skills. Instead we can value the role of care via monetary validation but not those caring skills that make up that role in and of itself.

Similarly, Fineman has argued that the right to care, whether a choice or not should be fiscally remunerated by the state.¹⁴⁶ This obligation is premised on the recognition of the value of care. Friedman's use of rights raises the question of whether there should be a right to care.

Herring distinguishes between Friedman's model and the moral claim that care is good for society and should therefore be facilitated. Friedman's justification of rights is premised on the concept that human beings have certain attributes which therefore promotes their status as rights holders. If this status-based approach is taken to justify the right to care I argue that it implies that there is some form of innate and natural disposition to care particular to the human being. The consequence of this is that we run the risk of reverting back to maternal and natural paradigms of care where care is seen as something known rather than learnt. This discriminates against those who do not "naturally" demonstrate caring qualities or force those who are perceived to be natural carers to undertake caring roles.

In contrast, Herring argues that the place of care in our daily lives means that we cannot separate it into an identifiable right. Moreover, Sevenhuijsen states that the practice of care

¹⁴⁵ J Herring, *Caring and the Law* (n69) 119.

¹⁴⁶ M A Fineman, *The Autonomy Myth* (n128).

itself is of central moral significance.¹⁴⁷ In agreement with Herring, “the right to care” is an alternative argument for care as a claim of morality. Therefore, if we are to position care as a right I argue that this is justified because of its instrumental value, in that protecting that right brings about an advantage to individuals and the community. By viewing the right to care as an instrumental consequence of bringing about an advantage to individuals and the community there is greater scope to use a care-based ethic as tool in policy making.

Viewing care as a social good provides a way to assess whether assisted dying is an example of care and whether this would be supported as a community good.

However, as Himmelweit argues, if care is to be considered a moral or social value, this does not mean that the state necessarily must support it (given there are many moral and social values which exist, but the state does not support).¹⁴⁸ Nevertheless, the growing costs and complexities of care, specifically with regards to the care of the individual who requests assistance, make a significant case for state responsibility for care. As Himmelweit notes,

Not to adopt a generous strategy for caring now will shift power away from those who continue to care, erode caring norms, and make it more difficult to adopt a more caring strategy in the future. Without such a strategy, standards and availability of care will fall with high cost to society as a whole and fall particularly heavily on those who continue to care.¹⁴⁹

Under this analysis, the state has an obligation to facilitate the relationship between familial members and the dying individual by providing both private and public systems of support for the practice of care.

What type of care should the state provide?

¹⁴⁷ S Sevenhuijsen, *Citizenship and the ethics of care*

¹⁴⁸ S Himmelweit, *Can We Afford (not) to Care: Prospects and Policy* (Open University, 2005).

¹⁴⁹ *ibid.*

Fineman suggests that societal institutions (as defined by the state) should provide the dependent individual with 'resilience or resources with which to respond in specific times of crisis or opportunity.'¹⁵⁰ Fineman argues that resources provide the individual with realistic choices which define the range of autonomous choices and acts they possess. These resources are categorised as human assets, physical assets, social assets, environmental assets and existential assets. I argue that the practice of care falls into both categories of 'crisis' and 'opportunity' that Fineman suggests. The care required for the individual who wishes to end their life discussed in the above sections illustrate just this. Care can ameliorate times of crisis and also be viewed as an opportunity to build positive private relationships. Therefore, government agencies have a responsibility to recognise the caring practices that exist in society, inclusive of those where the individual requests assistance to die.

As Sevenhuijsen argues, a political model of a care ethic should encourage interactive policy making. This means the government should be responsive supportive and organising of caring practices.¹⁵¹ Currently, the practice of care as a whole is positioned outside the centre of politics.¹⁵² Thus, the assisted dying debate may be at the centre of politics, yet caring for in the individual who requests assistance is placed outside of this political arena. State policy should be a progressive system which sees care taking a public role. This public role allows for the recognition of the unique subjectivity of individual lives, and the multiple forms and fragility of relationships. Although not directly related to care ethics, this draws similarities with Nedelsky's critique of liberal autonomy.¹⁵³ Nedelsky argues that the liberal definition of autonomy is a social construction. Instead we require a concept of autonomy that recognises our experience of embeddedness in relationships. Yet the liberal state categorises autonomy

¹⁵⁰ M A Fineman, 'The Vulnerable Subject' (n118).

¹⁵¹ S Sevenhuijsen, *Citizenship and the ethics of care* (n62).

¹⁵² C Smart and B Neale, *Family Fragments* (Polity Press 2007).

¹⁵³ J Nedelsky, 'Reconceiving Autonomy: Sources, Thoughts and Possibilities' (1989) *Yale Journal of Law and Feminism* (1).

as a right for the state to provide barriers which the state cannot cross or interfere with. This is certainly reflected in arguments in favour of assisted dying, which are often premised on rights-based arguments. Though Nedelsky's theory is grounded in a critique of liberal property theory, I agree that care is only considered an activity when it is deemed to exist in the private sphere. This then presents barriers to recognising the impact that public provision of care has on the positive interactional relationship in the private domain. Moreover, when the practice of care does become present in the public domain, it is reasoned on a property-based analysis. For example, Smart and Neale have noted that in the family courts, the parental role is typically defined as a right or entitlement rather than underpinned by the value of relational connectedness.¹⁵⁴ For the individual who requests assistance then, the appropriate use of a care ethic by government agencies is to recognise the positive relational interaction that exists and how best they can facilitate support by various public and private mechanisms.

For example, the creation and modification of policies should be inclusive of the flexibility for the care-giver to participate in contemporary public life but also be able to practice care in the private domain. For example, the care giver must be able to access employment but while in employment also have the ability to provide care. Indeed, Barnes has aptly described policy making as the ability to use the moral imagination to produce 'care-full'¹⁵⁵ policies that are inclusive of knowledge, emotional response and understanding of the issue at hand. Applying this to the care ethic suggested in this chapter, the state must be responsive to the caring roles and practices that the care-giver creates. Government agencies and state policies must be open to, and inclusive of, different caring practices than those traditionally caring

¹⁵⁴ C Smart and B Neale, *Family Fragments* (n149).

¹⁵⁵ M Barnes, *Care in everyday life* (n119).

obligations promoted in the private domain.¹⁵⁶ Having already argued earlier in this section that the promotion of caring relationships should be seen as a human right,¹⁵⁷ I argue that policies based on a care ethic should support the relationship between private relational interactions. What this means in reality is that there is a multiplicity of relationships that should be supported by various methods of state support. As noted in section four with regards to care, positive relationships can be described as efficient, impersonal or superficial, and equally described as substantive, emotionally connected and enduring. These experiences of care and the relationships that derive from them are reliant on both public and private care provisions. Thus, as Sevenhuijsen suggests, the state's facilitation of care is premised on the role of a supervisor to ensure that care is correctly attended to.¹⁵⁸ As such, by recognising the plurality of relational caring goals, then healthcare professionals, social care professionals and government agencies have a responsibility to ensure that the type of care which they provide prioritises the positive relationship in the private domain. In the current political climate however, it is perhaps an ideal view that the state takes a supervisory approach to the provision of a multiplicity of caring practices in the public and private domain. Therefore, a minimum level of state facilitation of care needs to be discussed.

What minimum level of state facilitation of care is appropriate?

In *The Heart of Justice*, Engster suggests six principles for care set at a minimally decent level as a basic response to state provision of care.¹⁵⁹ These principles include to help individuals meet their basic needs for survival such as nourishment, sanitary water and

¹⁵⁶ Arguably this transition is already in existence, though not complete. The rise of career parents, where paid childcare becomes the norm, the allowance of parental leave, for both male and female parents, and in the medical and social care sphere, patient choice programmes and personal budgets remain part of policy initiatives.¹⁵⁶ See further; F Williams, 'In and Beyond New Labour: Towards a New Political Ethics of Care' (2001) 21 *Critical Social Policy* 467.

¹⁵⁷ J Herring, *Caring and the Law* (n69).

¹⁵⁸ S Sevenhuijsen, *Citizenship and the ethics of care* (n62).

¹⁵⁹ D Engster, *The Heart of Justice* (OUP 2007).

shelter, and to enable individuals sustain their basic capabilities for cognitive activities when they cannot achieve these goals on their own. In addition, Engster argues that governments should organise or fund programs of care by incorporating the input of those within caring relationships. At the same time the government should ensure that the public are aware and can easily access the programmes of care available. This would mean that care would be delivered at a local and personal level like providing support to informal carers. Finally, and of important significance for the individual who requests assistance, Engster includes in his suggested principles, 'to help individuals to avoid and alleviate unnecessary pain and suffering when they need help in meeting this goal.'

Though I support Engster's approach as a basic minimum for state facilitation of care, it is noted that this is not inclusive of a positive relational interaction. If Engster's approach is promoted as a minimum level of state provision, then it must be inclusive of positive caring relational dynamics. Arguably this can be implicitly seen in Herring's work. In supporting Engster's basic decent minimum of care, Herring references this as the 'state's response to those in caring relationships' rather than the state's response to those who are vulnerable or are in need of care as isolated individuals. I agree with Herring's use of a basic response to care which is focussed on supporting relationships as this is a community good.

In application to assisted dying then, under Engster's basic response, the state's responsibility for the dying individual's survival and basic cognitive abilities does seem to include the dying individual. The individual may receive care that ensures that they are well nourished and hydrated, have access to a safe and suitable residence and have support to demonstrate cognitive abilities, such as machines which enable communication through eye movements. Importantly, under Engster's analysis, the state has a responsibility towards alleviating the potential pain and suffering the dying individual (and arguably those whom they are relationally associated with) may experience. At first blush, it seems that if assisted dying

alleviates the pain and suffering of the dying individual, then the state has a responsibility to facilitate this. However, Engster uses the phrase ‘*unnecessary* pain and suffering.’ I question how Engster defines unnecessary pain and suffering. Given that Engster’s other principles appear to support the continuum of life, one can argue that Engster’s approach could be interpreted as supporting sanctity of life principles. However, assisting the dying individual to die would remove the very pain and suffering which forms part of their existence. By prioritising life over the alleviation of suffering there is a risk that the practice of care is perceived as an activity that is only applicable to the maintenance of life. This could result in ignoring the other values that care contributes to society such as positive relationships and political movements.

If the state’s responsibility for care is to be of a minimum standard of ensuring the maintenance of life, it must be accepted that, under this definition, care cannot be inclusive of a state responsibility to facilitate assistance to help the dying individual end their life.

Arguably, then, the dying individual that wishes to end their life could experience conditions that may be cared for under a basic response but still experience pain and suffering due to the context of their condition.

If this is the case, then one can argue that any care required above the basic level, whether this is physical care labour, emotional support or fiscal support will be facilitated in the private domain. Given the complex physical care needs of the individual who requests assistance and the emotional context that this may have on relationships, a reasonable inference can be made that such experience could have a negative effect on private positive relational interaction. The use of Engster’s application is suitable for a care ethic that supports a practical application of physical care labour, but not one that supports the choice to die on behalf of the dying individual. Therefore, if Engster’s basic minimum level of care is to be applied to the state policy and the facilitation of care in the public and private domain

in the context of the individual who requests assistance, it must be improved by recognising that the ultimate goal of care is not necessarily the maintenance of life at all costs and that the alleviation of pain and suffering is inclusive of the possibility of ending the life of the care receiver.

I have argued that a care ethic should be premised on positive private relational interaction and the state's role should be to facilitate this relationship by providing both public and private systems of support which ensure a positive relationship between the relevant parties. However, where a definition of care is reliant on the state's role in the facilitation of private positive relational interaction by providing both private and public systems of support, the fiscal considerations of models of care requires review.

I argue that a care-based approach by government agencies is conducive to positive relationships and to society itself. (Though it is noted that a balance must be struck between ensuring successful and competent caring relationships with appropriately financed facilitation of care in the public domain.) This means that a minimal level of care needs to be established. However in response to the individual who requests assistance to die, a basic minimal approach that maintains life at the cost of assisting the individual to end their life could jeopardise the very understanding of care. Care could be stripped of its societal value, relational value and the ability to recognise the complexities and nuances which arise in different caring relationships. I therefore argue that state provision of care as a societal value as an important enabler of positive relational interaction in the private domain.

9. Summary

Commencing from Gilligan's work, this chapter has discussed how different care-based ethics can be applied to the individual roles involved in the assisting dying scenario. I have argued that the role of the dying individual in making decisions about their care is reliant on a process-based version of autonomy. In applying Meyer and Freidman's respective theories, I

have illustrated that a care orientated version of process-based autonomy emphasises the importance of considering the collection of attributes pertinent to the individual who requests assistance which are grounded in the realities of the individual's unique experience. This chapter then went on to discuss why the positive relational paradigm, specifically in Noddings's work, at the core of maternal care ethics, is still a valuable contribution to the role of care in the private and familial domain. However, it has been made clear that the positive relational interaction should not be premised on traditional nurturing roles, the romanticisation of care or biogenetic links. Therefore, for the purpose of this thesis, family is defined as a relationship that is chosen, with multiple forms of caring practices which are based on sentiment, emotion and material aid. It is from this basis that I have defined a care ethic as a private positive relational interaction and that the state's role should be to facilitate this relationship by providing both public and private systems of support. The different types of care that are appropriate for the individual who requests assistance have then been discussed in relation to healthcare and social care professionals respectively. I have argued that a principled and consequentialist approach to care, as per Tronto's account, is suitable for the healthcare professional and the social care professional. However, I have questioned whether there is a clear difference between the principles of attentiveness and responsiveness, and whether they both account for understanding of the individual care receiver's needs based on vulnerability. I have also argued that Tronto's principle of responsiveness should be understood as a literal and embodied response to the provision of care. In addition, given the social care professional's positioning in the private domain, their role should have an authentic desire to care which can be illustrated by Hammington's embodied response to care. The final section of this chapter argues that government agencies should use a care-based ethic as a way of generating policies which reflect care in response to the individual who requests assistance. Though I argue that care is morally valuable, due to fiscal

limitations, I have also included an analysis of Engster's minimally decent level of care, though it is questionable how far this supports the state's facilitation in assisting an individual to die. A care-based ethics helps us to better recognise the realities of care concerning requests for assistance to die. By doing this I have argued that regulation of assisted dying must support positive relationships in the private domain. The state has an obligation to facilitate these relationships by providing both public and private systems of support.

CHAPTER THREE: WHAT ARE THE CURRENT LEGAL FRAMEWORKS
CONCERNING ASSISTED DYING: CONTEMPORARY MEDICAL LAW CASES

1. Introduction

In this section I will discuss three contemporary medical law cases concerning assisted dying: *Aintree University Hospital NHS Foundation Trust v Aintree*¹⁶⁰, *Briggs v Briggs*¹⁶¹ and *Nicklinson*¹⁶². These cases have been selected in order to illustrate the connection between patients with capacity and those who lack capacity and how this informs our understanding of assisted dying. *Aintree* and *Briggs* will be used to analyse how the withdrawal of treatment from patients who lack capacity to consent is conceptualised and applied by the courts. With recourse to the Mental Capacity Act, the analysis of the judicial reasoning in these cases will focus on three primary issues concerned with withdrawal of treatment in the context of assisted dying; futility, the best interest test, and intending death. The Supreme Court decision in *Nicklinson* is included in this section as a way of bringing together the contemporary issues that surround assisting dying and how this can be compared to the legal frameworks concerning withdrawal of treatment.

2. *Aintree University Hospitals NHS Foundation Trust v James*: What is treatment and can we withdraw it?

The law makes it clear that taking the life of another person constitutes murder.¹⁶³ If the healthcare professional terminates the life of the patient, with the intention to bring about their death, no matter how compassionately, and regardless of the patient's consent the

¹⁶⁰ [2013] UKSC 67

¹⁶¹ [2016] EWCOP 53.

¹⁶² *Nicklinson* (n2).

¹⁶³ Murder is the unlawful killing of a human being in the Queen's Peace with malice afterthought. See further; *R v Woolin* [1999] AC 82; *R v Dr Bodkins Adams* [1957] Crim LR 365.

healthcare professional will be charged with murder.¹⁶⁴ Thus, ““mercy killing” by active means is murder(...) that the doctor’s motives are kindly for some, although not for all, transform the moral quality of the act, but this makes no difference in the law’.¹⁶⁵ There is potential then, that if the health care professional does not provide care they can be found criminally liable for the patient’s death.

This issue was brought to prominence in the seminal case of *Airedale NHS Trust v Bland*.¹⁶⁶ Mr Bland had suffered irreversible damage to his brain due to crush injuries experienced at Hillsborough football stadium. Mr Bland had no cortical function but his brain stem continued to function warranting a diagnosis of permanent (now persistent) vegetative state (PVS). In 1993, the House of Lords unanimously granted a declaration that it was lawful for doctors to discontinue artificial nutrition and hydration (ANH) which would lead to Mr Bland’s death, with this ANH characterised as medical treatment.¹⁶⁷

What is important for the discussion of assisted dying is whether we define (clinically) artificial nutrition and hydration as a treatment or as the provision of basic care. The complexities of this question are emphasised when applied to patients in a MCS. Unlike patients in PVS, patients in a MCS are often described as occupying a twilight world. MCS patients have a minimal amount of awareness and communication skills and can experience pleasure and pain (though this is difficult to objectively measure).¹⁶⁸ Because MCS patients can demonstrate behavioural evidence of self-awareness and/or awareness of the environment they inhabit this scenario offers a more nuanced approach than that of patients in a PVS *in analysing* the current legal framework concerning ANH.

¹⁶⁴ See further; *R v Cox* [1992] 12 BMLR 38.

¹⁶⁵ *Airedale NHS Trust v Bland* [1993] 1 All ER 821 Lord Mustill at p. 850

¹⁶⁶ *ibid.*

¹⁶⁷ *ibid.*

¹⁶⁸ See further; *Frenchay Healthcare NHS Trust v S* [1994] 2 All ER 403; *Re S (Adult Incompetent: Withdrawal of Treatment)* (2001) 65 BMLR 6; *Re D [Medical Treatment]* [1998] FLR 411; *Re H (A Patient)* [1998] FLR 36.

There are two options: the first is that ANH is a medical *treatment* and therefore can be withdrawn legally if it is considered futile. The second option is that ANH is considered *basic care*, akin to washing a patient, which cannot be considered futile and legally withdrawn.¹⁶⁹ Thus ANH could be considered as medical treatment if the insertion of the nasogastric tube and feeding solutions were administered and overseen by a medical professional. Yet nasogastric tubes for the purpose of ANH are also used within care settings and even familial members can be trained to administer such a therapy, whether this is in the private familial home or professional care setting. This means that ANH can be recast as a care-based practice. Keown argues that the definitional arguments concerning ANH are premised on the context that ANH is administered in;

A doctor may do many things in the course of his or her practice, such as reassuring patients or fitting catheters, which are not distinctively medical in nature. And, if it is opinion which is crucial, the answer one gets may well depend on whom one asks. Tube-feeding may be regarded as medical treatment by many doctors, but many nurses regard it as ordinary care.¹⁷⁰

I argue that how ANH is defined is dependent on the setting that the treatment is administered in.¹⁷¹ The case of *Aintree* provides a pertinent example of this. In *Aintree*, sixty-eight-year-old Mr James fell into a MCS after suffering complications from his cancer treatment. His awareness was described as very limited but was described as taking great enjoyment from recognising his family and close friends, often demonstrating facial expressions when hearing about family news or listening to music.¹⁷² The hospital treating Mr

¹⁶⁹ See further; E Jackson, *Medical Law Texts Cases and Materials* (OUP 3rd edn, 2013) 960-962.

¹⁷⁰ J Keown, 'The Case of Mrs B; suicide's slippery slope?' (2002) *Journal of Medical Ethics* 28.

¹⁷¹ For a further discussion see Keown; *ibid.*

¹⁷² *Aintree University Hospitals NHS Foundation Trust v David James (by his litigation friend, the Official Solicitor), May James, Julie James* [2013] EWCA Civ 65 [16].

James sought a declaration from the Court of Protection that if Mr James's condition deteriorated, that clinically assisted nutrition and hydration (CANH) could be lawfully removed which would then result in Mr James's death. This case predominantly concerned questions of futility which is beyond the scope of this thesis.¹⁷³ This section will instead focus on the setting of Mr James's care.

Because Mr James was in a clinical hospital and the ANH was predominantly administered by a medical professional, ANH should be deemed as treatment. This can be compared to *Briggs*, (the facts of the case will be discussed later in this chapter). Mr Briggs was in a care home, not a hospital, his treatment was described as palliative in nature rather than solely medical. Therefore in this instance, ANH could be defined as care.¹⁷⁴ So here we have two different scenarios; ANH as treatment because of the medical context and ANH as care because it is provided in care-based setting.

The consequences of this is that if ANH is characterised as a treatment it will be judged by a different standard to that of ANH characterised as care. By withdrawing *treatment* the health care professional is not causing the death of the patient. Yet, if *care* is withdrawn the health care professional is responsible for the death of the patient and takes a step closer to practicing passive euthanasia. This then conflates how we view the withdrawal of treatment – in some instances it exists near the borders of what we deem as “assisted dying” and in other instances it is an example of “assisted dying”. This will be further discussed in chapter four in a reconceptualisation of how we determine assistance to die.

How to determine when we should withdraw treatment

¹⁷³ In clarifying the meaning of “futility,” “recovery” and “overly burdensome” stated in the Mental Capacity Act Code of Practice, Lady Hale asserted that medical outcomes still play a part in the determination of futility but they are to be weighed against the subjective values that the patient holds.

¹⁷⁴ This is similar to the Supreme Court decision in *Cuthbertson v Rasouli* [2013] SCC 53. In this instance if ANH is considered treatment it can be withdrawn. If it is deemed as palliative then it cannot be withdrawn.

Without capacity to consent to the withdrawal of treatment, the decision to withdraw treatment from the minimally conscious patient is governed by the Mental Capacity Act 2005 (MCA).¹⁷⁵ If it is deemed that the patient lacks capacity the MCA provides a framework to enable a substitute judgment to be made. This substitute judgment is made in consideration of what would be in the best interest of the individual. Alongside the best interest test, the MCA also provides a regulatory framework to administer advance directives and power of attorney.¹⁷⁶ For the purpose of this chapter attention will be placed on the best interest test. Section four of the MCA states that the decision-maker must so far as is reasonable consider;

- (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.¹⁷⁷

This test requires a difficult balance between a subjective and objective interpretation to be made. However it was made clear in the MCA's practice notes that the best interest test did not constitute a substituted judgment test.¹⁷⁸ Section five of the MCA also states that where the determination of best interests is concerned with life-sustaining treatment, the decision-maker must not be motivated by the desire to bring about death.¹⁷⁹ However the line between the best interest test and substituted judgment test is somewhat blurred. As Brazier notes, "best interests" is a phrase easy to utter and difficult to interpret. It inevitably involves

¹⁷⁵ The Mental Capacity Act 2005 (MCA).

¹⁷⁶ MCA s9.

¹⁷⁷ MCA s4 (4).

¹⁷⁸ Explanatory Notes to the Mental Capacity Act 2005 paragraph 28.

¹⁷⁹ MCA s5 (4).

judgments of quality of life.¹⁸⁰ The following discussion of judicial reasoning illustrates just this.

¹⁸⁰ M Brazier, *Medicine Patients and the Law* (3rd edn, Penguin Group 2003) 452-453.

A substituted judgment– The approach in Briggs

Buchanan and Brock define a substituted judgment as acting according to what the individual who lacked capacity would choose if they did have capacity. In contrast, the best interest test is defined as acting to promote the optimum welfare interests for the patient in an evaluation of each option available.¹⁸¹ The Explanatory Notes to the MCA expressly state that the best interest test is not a substituted judgment test. This has also been affirmed by Lady Hale in *Aintree*¹⁸² and by Charles J in *Briggs*;¹⁸³ a substituted judgment is inclusive of but not determinative of the best interest test. The best interest test and substituted judgment test differ in the weight assigned to the various interests concerned with the individual. The best interest test places weight (although not necessarily equal) on each interest and weighs them up comparatively. In contrast, a substituted judgment test takes a narrower view and places sole emphasis on what the individual who lacked capacity would have wanted. It is also important to note here that the substituted judgment test is not the same as surrogate decision-making. This is a process by which the courts will nominate an individual to make decisions on behalf of the individual who lacks capacity.¹⁸⁴

Up until *Aintree*, it was typical for cases concerning the withdrawal of treatment to emphasise the sanctity of life.¹⁸⁵ Yet for Lady Hale, the purpose of the best interest test was ‘to consider matters from the patient’s point of view’¹⁸⁶ with emphasis placed on familial opinion.¹⁸⁷ Lady Hale’s approach redefined the emphasis placed on the role of wishes and feelings in the

¹⁸¹ A Buchanan and D Brock, *Deciding for others: The Ethics of Surrogate Decision Making* (4th edn, CUP 1990) 10.

¹⁸² *Aintree* (n9) [24].

¹⁸³ *Briggs* (n10) [20].

¹⁸⁴ See further the case of Terry Schiavo; *Michael Schiavo, as Guardian of the person of Theresa Marie Schiavo, Petitioner, v. Jeb Bush, Governor of the State of Florida, and Charlie Crist, Attorney General of the State of Florida, Respondents*, Case No. 03-008212-CI-20.

¹⁸⁵ See further Baker J in *W v M* [2011] EWHC 2443 at [249].

¹⁸⁶ *Aintree* (n9) at [45].

¹⁸⁷ *ibid* [40]-[42].

calculation of best interests. Recently, the Law Commission published their report on Mental Capacity and Deprivation of Liberty. The report recommends that the factors engaged in the best interest test should be recalibrated with particular weight attached to the wishes and feelings ascertained.¹⁸⁸ Given this, and in evaluation of subsequent case law since *Aintree*, most evidently in *Briggs*, I argue that a substituted judgment test has the potential to be increasingly deployed under the guise of the best interest test. This is evident in Charles J's reasoning in *Briggs*.

At paragraph [57] Charles J expressly stated that he was applying a best interest.

'The test is not a "what P would have done test", it is a best interests test and so a test that requires the decision maker to perform a weighing or balancing exercise between a range of divergent and competing factors.'

However, it is questionable how much "balancing" was undertaken by Charles J. I argue that the use of this balancing act was a gloss on a substituted judgement, heavily reliant on evidence provided by Mr Briggs's wife. This is illustrated by Charles J's "balancing" of the sanctity of life against the familial evidence of Mr Briggs's wishes and feelings. As discussed above, Lady Hale's dicta in *Aintree* and the House of Lords judgment in *Bland* weakens the emphasis on the principle of the sanctity of life in favour of a quality of life assessment.

Charles J's dicta places the sanctity of life as an extreme position at one end of a spectrum and quality of life at the other end of the spectrum. A quality of life assessment is only used briefly and instead places considerable weight on the importance of respecting Mr Briggs's self-determination premised on the speculative substituted judgment.

'The totality of the family evidence has convinced me in the sense that I am sure (and so have no reasonable doubt) that if Mr Briggs had heard the evidence and argument that I have, including the evidence about his best case scenario and the possible

¹⁸⁸ Law Commission, *Mental Capacity and Deprivation of Liberty* March 2017 Law Com No 372 pages 156-161.

distress, pain and difficulties he and his family may face if his CANH treatment is not continued he would have would have decided not to give consent to the continuation of his CANH treatment.’¹⁸⁹

Charles J discussed both evidence provided from Mr Briggs’s family, friends and colleagues and medical opinion. Charles J’s judgment is significant because of the emphasis that is placed between the two opinions. Charles J made the evidence from family, friends and colleagues as a significant sub-division of his reasoning. Not only did Charles J discuss the evidence given but also then spent a considerable amount of time justifying the weight he places on the familial evidence. Comparatively, Charles J considered that there is no need for an extended analysis of medical opinion; stating that the medical opinion discussed in the overview of the judgment was sufficient. Even before Charles J tried to “weigh up” these factors there is a clear presumption on the benefits of familial evidence of Mr Briggs’s wishes and feelings. Charles J’s reasoning reflects Brostrom’s *et al*’s arguments that a substituted judgment test is neither directed to be an adequacy condition for decisions or as a tool to understand the mind of the individual who lacks capacity.¹⁹⁰ As Brostrom *et al* argue how one should imagine what the patient wants is a complex task.¹⁹¹ They have suggested that there is a conceptual and practical difference between the incompetent individual’s wants, values and what they would consent to.¹⁹²

Without this direction, there is potential that the hypothetical scenarios that a substituted judgment-maker is encouraged to consider are underdeveloped.

Although *Briggs* was not a case that involved assisted dying, what is significant is the broad range of witness opinions used. This included Mr Briggs’s wife, mother, two brothers, sister-

¹⁸⁹ *Briggs* (n10) [101].

¹⁹⁰ Brostrom et al, ‘What the patient would have decided: A fundamental problem with the substituted judgment standard’ (2006) *Med Health Care Philos* 10 (3).

¹⁹¹ *ibid.*

¹⁹² *ibid.*

in-law and a police colleague. A useful comparison can be drawn with Sir Stephen Brown's dicta in *Bland*.¹⁹³ In *Bland*, only two familial witnesses were used; Mr Bland's father provided oral evidence while Mr Bland's mother provided a witness statement. Importantly as Dresser argues, 'in this emotional, uncertain and socially complex situation, specific interpretations of substituted judgments are unlikely to have much impact on the surrogate's choices.'¹⁹⁴ However, by having the widest spectrum of familial evidence available there is a greater chance that the court get a representative view of the individual and have the potential to minimise the effects of the emotional and complex situation presented to familial members.

This can be contrasted against Pauffley J's dicta in *United Lincolnshire NHS Trust v N*.¹⁹⁵ In a similar set of facts to *Briggs*, the case concerned the continued treatment of a patient (N) in a MCS. Pauffley J determined that it would be lawful to discontinue treatment based on a single conversation N had with her friend where she said she would not want to live with reduced capacity. Though Pauffley J followed a balance sheet framework,¹⁹⁶ the decision made was virtually determined on the evidence stating what N would have wanted. This demonstrates another step closer to a substituted judgment test and also raises expected questions concerning the reliability of evidence of what the individual would have wanted. For example, in a study completed by 2595 surrogate-patient pairs predicted the patients' treatment preferences with a 68% accuracy rate with this rate failing to increase after the pairs were given the opportunity for prior discussion of treatment preferences.¹⁹⁷

Withdrawing or continuing treatment –intending death?

¹⁹³ *Airedale NHS Trust v Bland* (n133).

¹⁹⁴ R Dresser, 'Substituted judgment in real life' (2015) *JMed Ethics* 41 (9).

¹⁹⁵ [2014] EWCOP 16

¹⁹⁶ *ibid* at [58].

¹⁹⁷ D Shalowitz *et al*, 'The accuracy of surrogate decision makers: a systematic review (2006) *Arch Intern Med* 166 (5).

The removal of treatment from patients who cannot consent has often concerned whether we desire the death of the patient. This is significant because Lady Hale expressly reflected section 5(5) of the MCA;¹⁹⁸ that the goal of withdrawal of treatment must not, in considering what is the best interest of the patient, be motivated by the desire to bring about death.

However, in *Briggs*,¹⁹⁹ Charles J blurred this conceptual distinction.

The facts of *Briggs* are like that of *Aintree*. After being injured in a road traffic collision, Mr Briggs suffered severe and permanent brain damage which resulted in a diagnosis of a MCS. At the time of the hearing, Mr Briggs was in a stable condition and was between MCS- (demonstrating non-reflex movements) and MCS+ (command following).²⁰⁰ It was argued by Mr Briggs's medical team that Mr Briggs could, with a further six months of rehabilitation, be able to demonstrate emotion and answer rudimentary questions about his feelings. The most realistic best-case scenario for Mr Briggs was that he was happy, had the ability to make basic decisions, have both pleasurable and painful experiences, be severely physically disabled, require twenty-four-hour care but would be unlikely to be depressed given that he could not contemplate his pre-injury life and pre-injury wishes and feelings.²⁰¹ Charles J decided that continuing CANH and the potential of extended rehabilitation was not in Mr Briggs's best interest.

At the start of his reasoning Charles J clarified that '[t]he test I must apply is not whether Mr Briggs should live or die.' However, in application to 4(4)(a) of the best interest test, Charles J argued that Mr Briggs's wishes and feelings could have been motivated by wanting to die.

Charles J asserted that section 4(5) prohibited the central argument made by Mr Briggs's

¹⁹⁸ MCA 4(5).

¹⁹⁹ *Briggs* (n10).

²⁰⁰ *ibid* [31]. For a discussion of the MCS spectrum see further; M Bruno *et al*, 'From unresponsive wakefulness to minimally conscious PLUS and functional locked-in syndromes: recent advances in our understanding of disorders of consciousness' *J Neurol* (2011).

²⁰¹ *Briggs* (n10) [51].

wife; that death in this circumstance is what Mr Briggs would have wanted.²⁰² On this account, the court did not have a desire to bring about Mr Briggs's death but rather analysed Mr Briggs's best interest with reference to his wishes and feelings which entailed wanting to die.²⁰³ Under a best interest analysis then, it is inconsistent to ignore the fact that death could be a valid feeling or wish that the individual who lacks capacity may have desired given consideration of their circumstances.

Charles J's approach illustrates the importance of conceptualising "intending death." It seems paradoxical that we recognise that death is a valid decision for patients whom have capacity but will not recognise this for patients who lack capacity. Intending death can be a factor to be weighed within the wishes and feelings of the patient who lacks capacity. This does not mean that the healthcare professionals or court wish the patient to die, but rather that out of the options open to the patient, death is the most suitable. Should the approach in *Briggs* continue to be applied, this then goes some way in realigning the law governing withdrawal of treatment of those who lack capacity with those who choose to refuse treatment. Though it is arguable that gaining evidence to prove that the individual who lacked capacity desired death is challenging, this is not to say that the courts should not undertake this task. As discussed in the following section, evidentiary support for best interest tests can be successfully gained and confidently relied on by the court.

Substituted judgment test – a wider application

It is here where dementia and questions of capacity highlight important distinctions concerning the MCA, end of life care and assisted dying. Where the dementia patient lacks capacity but still has the ability, in some way like the MCS patient, to demonstrate preferences about what they wish to do in daily life raises questions about what type of capacity mechanisms should be deployed in the assisted dying scenario. Given this and the

²⁰² *ibid* [92].

²⁰³ See *Re B (Consent to Treatment: Capacity)* [2002] 1 FLR 1090.

fact that, arguably, the courts are increasingly moving towards a substituted judgment test, there is an added complexity to the debate between the application of a best interest test and substituted interest test.

This debate is often underpinned by Dworkin's discussion of critical and experiential interests.²⁰⁴ As discussed in chapter two, critical interests are values and beliefs which direct one's own life. For example, the choice to be a vegetarian because the individual believes that animals are owed the same moral worth as human beings. Experiential interests are those interests which we enjoy instrumentally. For example eating chocolate provides pleasure and enjoyment but I do not believe that the consumption of chocolate is a value I hold as significant and formative of my life goals. So then, a substituted judgment reflects the critical interests.

In application to the facts of *Briggs*, Mr Briggs was described as risk taker; he previously stated that he did not think it was appropriate for children (like his own) to visit patients in a state like his. Mr Briggs's previous interests supported the contention that withdrawal of treatment was what he would have wanted. At first blush then, it appears that critical interests or prior directive choice should take priority over experiential or current values and wishes. However, as Dresser argues, is choice not irrelevant if one lacks the capacity to choose?²⁰⁵ Do we not have current interests in a continued life? Thus for individuals in a MCS and those with later-stage dementia, how we make decisions on their behalf and whether this includes activities that constitute assisted dying become complex. Notably, under an application of a substituted judgment test, there have been concerns raised about familial competency and

²⁰⁴ R Dworkin, *Life's Dominion* (n41).

²⁰⁵ R Dresser, 'Life Death and incompetent patients: conceptual infirmities and hidden values in the law' (1986) *Arizona Law Review* 28. See further; R Dresser and JH Robertson, 'Quality of life and non-treatment decisions for incompetent patients: A critique of the orthodox approach' (1989) *Journal of Law Medicine and Ethics* 17(3).

misrepresentation of the dying individual's views.²⁰⁶ Studies have found that options concerning the end of life and conditions such as MCS were not discussed with familial members, and when discussed, familial members incorrectly estimated the patients' values and choices. In addition, Dresser has claimed that although personal identity can be maintained as the same, there is no particular reason why the individual in the past would determine the present individual's wishes.²⁰⁷ This then hints that a best interest test which weighs up the competing interests between critical and experiential interests is superior to that of a substituted judgement test.

As Herring notes, 'even though a person is judged to be lacking capacity and their views are thus no longer protected by the right of autonomy, their preferences do still count for something.'²⁰⁸ These preferences reflect section four's 'present wishes and feelings' of the MCA. For example, Mr Briggs took some level of pleasure from interaction with family and care professionals. It is here, and perhaps more evidently with individuals who live with dementia, that current views and feelings should carry some weight in determining the decision at hand. Importantly, Herring appears to justify his argument from concepts of dignity and liberty.²⁰⁹ Though this chapter does not have scope to discuss the theoretical underpinnings of these concepts, what can be noted is that Herring's example is premised on the harm caused by ignoring dignity and liberty rights.

This is akin to Feinberg's account of honouring past preferences for future orientated interests.²¹⁰ Feinberg argues that patients who lack capacity still retain an interest in their existence and the potential circumstances of their death. Therefore, and as Dresser notes,

²⁰⁶ See further M Donnelly, *Healthcare Decision-making and the Law; Autonomy Capacity and the Limits of Liberalism* (CUP 2010) 191 – 192. Note however, that these concerns are associated with surrogate decision-making rather than a substituted judgment test.

²⁰⁷ R Dresser, 'Life Death and incompetent patients (...)' (n200).

²⁰⁸ J Herring, 'Losing it? Losing what? The law and dementia' (2009) *Child and Family Law Quarterly* (3) 16.

²⁰⁹ *ibid.*

²¹⁰ J Feinberg, *The Moral Limits of the Criminal Law: Volume One* (1984 OUP) 92.

respect for patients in their former competent states demonstrates respect for past preferences. This then brings us to the question of how we balance current preferences with past preferences and ultimately how this reflects our respect for individual autonomy. Arguably, the fact that a substituted judgment is part of the best interest test demonstrates at least some trust and validity placed in the mechanism. Though there are valid apprehensions about familial competency and misrepresentation I argue that this is not a reason to discredit the value a substituted judgment test has.²¹¹ There will, of course, be occasions where evidence from familial members are conflicting or unclear. Indeed, the sincerity of comments made by individuals will require evaluation. Yet I argue this is the judiciary's role. This evaluation may be challenging but it is certainly not impossible. I therefore argue that a balance should be struck between past preferences (i.e. a substituted judgment test) and current interests of the individual in question. I do not think it is necessary to apply a normative judgment of where weight should be applied as this defeats the purpose of assessing the values unique to the individual in question. Therefore, decision making on behalf of patients who lack capacity assessments should be inclusive of an evaluation of both current and prior choice. Having established that a more balanced best interest test places a greater and more comprehensive emphasis on a substituted judgment test, the following section will discuss the case of *Nicklinson*. This will illustrate the differences in legal regulation between those with capacity and without and to also highlight theoretical arguments that underpin the assisted dying debate.

²¹¹ Notably, prior to the MCA statutory wills were governed by a substituted judgment which required the judge to consider the affections of the particular individual. See further *Re D (J)* [1982] Ch 237.

3. The Case of *Nicklinson*: tying together arguments

Mr Nicklinson suffered a stroke which resulted in complete paralysis save for eye movement. *Nicklinson*²¹² concerned the legality of the Suicide Act 1961. In the first appeal, Mr Nicklinson sought a declaration that the prohibition on assisted suicide was incompatible with his right to a private life under Article 8 of the Human Rights Convention. After the High Court refused to grant a declaration, Mr Nicklinson refused food and water and subsequently died. Mr Nicklinson's wife and a second claimant named Mr Lamb were then added as parties to the proceedings. In 1991, after a car accident Mr Lamb was left paralysed save for movement in his right hand. Like Mr Nicklinson, Mr Lamb wished to end his life. A final appeal, and already briefly discussed in section four was added by the claimant known only as 'Martin.' In 2008, Martin suffered a brain-stem stroke which meant that he is almost incapable of movement. Martin wanted clarification from the DPP that a health or social care professional could assist him to die. By a majority of seven to two, the Supreme Court dismissed the appeal brought by Mr Nicklinson and Mr Lamb. In regard to Martin's claim, the Supreme Court unanimously allowed the appeal brought by the DPP.

Two significant cases had come before *Nicklinson*. In *R (Pretty) v Director of Public Prosecutions*²¹³ Diane Pretty was living with motor neurone disease and wished to end her life. In order to die she would require the assistance of her husband. She requested that her husband would be given a guarantee that he would not be prosecuted if he helped her to die. After her appeal was dismissed by the Lords the ECHR rejected her claim that a right to life did not include a right to choose when to die. As such, quality of life could not be interpreted as a right to die. In *R (Purdy) v Director of Public Prosecutions*²¹⁴ Debbie Purdy wanted to travel to Switzerland for the purpose of assisted dying due to a diagnosis of progressive

²¹² *Nicklinson* (n2).

²¹³ [2002] 1 AC 800.

²¹⁴ [2010] 1 AC 345.

multiple sclerosis. In order to travel to Switzerland she would require assistance from her husband. Debbie Purdy petitioned the Court to require the DPP to use guidance as to when prosecutions would be brought in similar cases to hers. The House of Lords upheld her appeal and the DPP were directed to produce guidance. The significance of *Nicklinson* however, lies in the dicta of Lord Neuberger, Lord Mance, Lord Wilson, Lord Kerr and Lady Hale. Their reasoning will be used to illustrate the issues concerning the current legal framework. The first issue discussed concerned the inconsistency between the law governing withdrawal of treatment and patients with capacity but who require physical assistance to end their life.

Legal inconsistencies

Lord Neuberger, Lord Mance and Lord Wilson were sympathetic to the circumstances of the appellants, recognising that the law concerning suicide was inconsistent with those who are unable, because of a physical disability, to end their life. Given that Parliament were debating the Assisted Dying (No1) Bill at the time of the appeal, Lord Neuberger refused to make a declaration of incompatibility due to concerns of constitutional legitimacy. Similarly, Lord Mance refused to make a declaration because of the appellant's reliance on secondary (rather than first-hand) evidence. In their dissenting judgments Lady Hale and Lord Kerr concluded that issues of constitutional legitimacy would not prevent them from making a declaration of incompatibility and also highlighted the importance of legal inconsistencies within the assisted dying debate. As Lord Kerr noted,

‘if the store put on the sanctity of life cannot justify a ban on suicide by the able-bodied, it is difficult to see how it can justify prohibiting a physically incapable person from seeking assistance to bring about the end of their life.’²¹⁵

²¹⁵ *Nicklinson* (n2) Lord Kerr at [358].

From this position, patients with capacity who refuse treatment and those, like Mr Nicklinson, Mr Lamb and Martin who require assistance to end their life can be compared. This was emphasised by Lady Hale’s discussion of *Re B (Adult Refusal of Medical Treatment)*.²¹⁶ Aged forty-three, Ms B became paralysed with some use of her head and neck muscles. Ms B was reliant on artificial ventilation. Without this ventilation Ms B would only have a 1% chance of living. Ms B sought a declaration from the High Court that she had the capacity to refuse treatment. Dame Butler-Sloss made a declaration that Ms B did have capacity to consent to or refuse life sustaining treatment and awarded nominal damages. It is perhaps a blessing (for want of a better phrase) that Ms B was receiving life-sustaining treatment (artificial ventilation) which by refusal, gave her the opportunity to die without legal culpability of anyone else involved. Yet this is not the case for individuals like Mr Nicklinson, Mr Lamb and Martin. The distinction between a positive (killing) act and a negative act (letting die) does indeed exist, but this distinction is theoretically complex. As Singer argues, refusal of treatment and requests for assistance to die are shaped by two separate legally consistent doctrines.²¹⁷ Thus the comparative outcomes of *Re B* and *Nicklinson* are entirely predictable. Yet it is the ethical underpinning to the two scenarios which rest on an uneasy moral foundation. I argue that, in the assisted dying scenario, our autonomy rights and the moral value we attach to the facilitation of such rights underlies this ethical or moral foundation.²¹⁸ Lord Neuberger highlights just this,

‘Indeed, authorising a third party to switch off a person’s life support machine, as in *Bland* or *Re B (Treatment)* seems to me, at least arguably, to be, in some respects, a more drastic interference in that person’s life and a more extreme moral step, than

²¹⁶ [2002] EWHC 429 (Fam); *Nicklinson* (n2) [302]-[304].

²¹⁷ P Singer, ‘Mrs B and Dianne Pretty: A Commentary’ (2002) *Journal of Medical Ethics* 28.

²¹⁸ Lady Hale gets at this in *Nicklinson* (n2) at [304].

authorising a third party to set up a lethal drug delivery system so that a person can, but only if he wishes, activate the system to administer a lethal drug.’²¹⁹

Singer argues that instead of taking a rule-based approach to these scenarios a consequentialist approach should be considered.²²⁰ Therefore, the decision to permit assistance for individuals like Mr Nicklinson to die should be premised on the condition or circumstance that would remain if permission was not granted. However, I argue that the use of a consequentialist ethic actually encourages normative understandings of suffering and living with disability. Thus what may result is an arbitrary application of legally permissible assistance based on an objective understanding of individual circumstances. This can be illustrated by Maclean’s analysis of refusal of treatment cases.²²¹ Maclean argues that often where refusal of treatment is not granted it is because the judge views that individual’s life as still being worthwhile. Yet if this is contrasted with the reasoning in *Re B* what can be seen is the emphasis on personal autonomy. *Re B* lacked an in-depth analysis of personal autonomy. If this analysis had been taken further what *could* have emerged was an analysis of autonomy rights which provided the potential for a closer alignment between the law governing refusal of treatment and the law governing requests for assistance to die. These legal inconsistencies underpin a potential but underdeveloped argument in *Nicklinson*, namely, that there is a right to die in UK law.

Is there a right to die?

The House of Lords in *Pretty* declared that there was no right to die and that Article 8 was not engaged. Yet at Strasbourg, Article 8 was found to be engaged, though agreeing that the interference of the Suicide Act was justified under Article 8(2). This was affirmed in *Purdy*,

²¹⁹ *Nicklinson* (n2) para [94].

²²⁰ P Singer, ‘Mrs B and Dianne Pretty: A Commentary’ (n214).

²²¹ A Maclean, ‘Advanced directives and the rocky waters of anticipatory decision-making’ (2006) *Medical Law Rev* 14.

where the House of Lords recognised the engagement of Article 8 and ordered the DPP to publish guidelines to prevent an unjustified interference with Article 8(2). However, since *Purdy*, Strasbourg jurisprudence concerning assisted dying has developed further. In *Hass v Switzerland*²²² and confirmed by *Koch v Germany*²²³ the court recognised that respect for private life under Article 8 can be interpreted as ‘an individual’s right to decide by what means and at what point his or her life will end.’²²⁴ It can therefore be said that under the Convention, there is a right to die. However, the continued Strasbourg jurisprudence has not viewed the state or other third parties as having a correlative right to assist. Instead, the courts have decided what constitutes an interference with the right on a case-by-case basis. For example, in *Gross v Switzerland* the Strasbourg court ruled that a lack of guidelines of what circumstances a doctor could prescribe a lethal dose to an individual not suffering from a terminal illness was a violation of Article 8.

Who should assist?

The explicit recognition of the potential role of the healthcare professional in participating in assisted dying raises the popular debate of whether physician-assisted suicide should be legalised. Due to the scope of this chapter I will not touch on this debate in depth. However, the consequence of the prohibition on physician-assisted suicide is an important point to make. If “suicide tourism” is not an option, it is likely that a family member will assist the dying individual to end their life. This means that if assistance mirrors the facts of *Hough* there is a potential that death will not be “pleasant.” As Mullock asks, “will there be botched jobs?”²²⁵ Mullock provides the case of *Gillderdale* as a pertinent example of this.²²⁶

²²² [2011] ECHR 2422.

²²³ Application no. 497/09

²²⁴ *ibid* para [51].

²²⁵ A Mullock, ‘Overlooking the criminally compassionate: what are the implications of prosecutorial policy on encouraging or assisting suicide?’ (2010) 18 (4) *Med Law Rev*

²²⁶ *R v Kay Gillderdale* - (Lewes Crown Court, Jan 2010)

Gillderdale's daughter, Lyn, suffered from MS and was reliant on intimate personal care. Because of this, Lyn wanted to end her life. Gillderdale provided two doses of morphine which Lyn administered herself. Unfortunately, the dosage did not bring about Lyn's death so her mother found tablets in her home, crushed these with a mortar and pestle and administered them through Lyn's nasogastric tube. This did not cause Lyn to die and so Gillderdale had to administer two or three more morphine syringes which then caused an air embolism in the vein. Finally, eight more tablets were administered and Lyn died. Within those thirty hours Gillderdale also rang a euthanasia charity and searched the internet with terms relating to voluntary euthanasia and morphine overdoses. I detail the facts of this case to illustrate the potential types of assisted suicide that the DPP's non-prosecutorial policy could yield. More recently, a ninety-five-year-old man attempted to kill his wife with a hammer blow to the head because she did not want to die in a care home or hospital.²²⁷ By making prosecution of healthcare professionals and professional carers extremely likely and with BMA guidance warning healthcare professionals not to engage in any type of discussion of assisted dying, the current legal framework is hazardous. It prevents those requiring assistance drawing upon medical and health care knowledge which has the potential to ensure a more painless and "effective" death as compared to the deaths described above.

Protection of the vulnerable

The most substantial concern raised in *Nicklinson* was the protection of the vulnerable from duress or pressure; the sentiment being that a blanket ban on assisted dying is the only way to ensure sufficient protective safeguards. As Lord Sumption suggested;

²²⁷ The Telegraph, 'Man, 95, spared jail over attempted mercy killing of wife who showed 'true love' by forgiving him' <<http://www.telegraph.co.uk/news/2017/04/25/man-95-spared-jail-attempted-mercy-killing-wife-judge-said-showed/>> accessed 22 May 2017.

‘If it is lawful for a third party to encourage or assist the suicide of a person who has chosen death with a clear head, free of external pressures, the potential arises for him to encourage or assist others who are in a less good position to decide.’²²⁸

The protection of the vulnerable is a legitimate argument for the criminalisation of assisted suicide. Yet I will argue in the following paragraphs, with recourse to both Lady Hale and Lord Kerr’s dissents, that this objection is over-emphasised.

Theorists such as Keown have argued that legalising or decriminalising assisted dying practices would lead to non-voluntary euthanasia (this is where the individual is unable to consent typically due to capacity or age issues) or involuntary euthanasia (this is where the individual is able to consent but has not done so. In this instance euthanasia is practiced without their permission). Known as the slippery slope argument, the main contention is that we should not assist individuals like Mr Nicklinson because involuntary assisted dying could be a side-effect of such assistance. However, in the most recent empirical evidence cited from jurisdictions where assisted dying has been legalised,²²⁹ it has been shown that there is no necessary connection between increases in passive suicide (withdrawal or withholding treatment) to the termination of life without explicit request. Importantly, no law is infallible, that there may be cases which ‘slip through the net’ yet these should not be used as evidence to support a causal link between assisted dying and non-voluntary euthanasia.

In addition, I argue that a complete blanket ban characterises any individual with a disability as automatically opposed to assist dying for the reasons discussed above. This ‘one-sided precautionary argument’²³⁰ fails to recognise that disability groups may oppose the legalisation of assisted dying but disabled individuals can think the contrary. For example,

²²⁸ *Nicklinson* (n2) at [215]

²²⁹ S W Smith, *End of life Decisions in Medical Care: Principles and Policies for Regulating the Dying Process* (CUP 2012).

²³⁰ R Brownsword *et al*, ‘Prospective Legal Immunity and Assistance with Dying: Submission to the Commission on Assisted Dying (2012) 23 *King’s Law Journal* 185.

75% of people with a disability who participated in the 2005 British Social Attitudes Survey supported legislation in favour of assisted dying.²³¹ Notably, as mentioned earlier in this section, every case brought before the courts concerned disabled individuals. It was the very experience of living with this disability that caused them to challenge the current legal framework. Given that the DPP's statistics on investigating possible prosecutions suggest assisted dying is happening "underground"²³² a blanket ban is not the solution to safeguarding the vulnerable but rather an argument in favour of ensuring sufficient and robust regulatory mechanism which ensures the presence of capacity and autonomy.

Biggs has suggested that additional safeguards could have been added to The Assisted Dying (No 1) Bill by way of a declaration made in isolation to those who have the potential to exert influence over the dying individual.²³³ I raise this point because the argument highlighted by Biggs misses two important realities of the effects of assisted dying. Given the statistics produced by the CPS (which do not illustrate patterns of undue influence) I would question how likely the presence of duress and undue influence is in the assisted dying scenario. In addition, I would argue that if influence was used that this had been a process which was acted out over a relatively long period of time and that a formalised isolated declaration of signing documents is unlikely to remedy the influence already exerted. Moreover, as discussed in chapter one, in the assisted dying scenario, it is not beneficial to make decisions in isolation away from those who care for the dying individual. A more persuasive argument to that of Biggs's isolated declaratory procedure is to ensure that assisted dying remains a legal option amongst other *equally good* care options which is inclusive of the ability to discuss assisted dying with the relevant care-based professionals.

²³¹ E Clery *et al*, 'Quickening Death: The Euthanasia Debate' in A. Park *et al* (Eds), *British Social Attitudes: 2006 – 2007, The 23rd Report* (London, UK: Sage, 2007).

²³² For a description of these scenarios see further; R Magnusson, *Angels of Death: Exploring Euthanasia Underground* (Yale University Press 2002).

²³³ H Biggs, 'The Assisted Dying for the Terminally Ill Bill 2004: Will English Law Soon Allow Patients the Choice to Die?' 2005 *European Journal of Health Law* 12 43-56.

Lady Hale did not see it impracticable to create a legal framework, inclusive of safeguards for assisted dying. Indeed, it also appeared that Lord Neuberger, Lord Wilson and Lord Mance were also willing if the circumstances of the case were different to agree with Lady Hale and Lord Kerr's dissent. The decision in *Nicklinson* then is a progression from the somewhat conservative approach taken in *Pretty*. But this progression is not much more than a signal that the court, in the future, could be willing to allow a limited exception to the prohibition on assisted suicide. It appears then that if a new case presented slightly different arguments to those submitted in *Nicklinson* a majority of five-four would have been produced. The case of Neil Conway had the potential to provide this opportunity. However, the arguments provided by Mr Conway take a narrower view than those in *Nicklinson* and replicate the failed Assisted Dying Bill. Thus, it is unlikely that if his case reaches the appellate courts that a declaration of incompatibility will be made.

4. Summary

This chapter has predominantly focussed on scenarios where patients are in a minimally conscious state and have used the respective judgments of *Briggs v Briggs* and *Aintree v James* respectively. By discussing these cases I have illustrated the disadvantages and advantages of a best interest test as opposed to a substituted judgment test. I have argued that the appropriate approach is to apply a best interest approach but only if this is inclusive of a comprehensive application of a substituted judgment as part of this test. By using this approach, a more representative decision-making process can be achieved with questions such as intending death being inclusive of this analysis. In this chapter I then applied this approach to those living with dementia who request assistance to die using an advance directive. I have argued that honouring an advance directive which disregards the current wishes and feelings of patient in later stages of dementia comes to close to the line drawn between active and passive euthanasia. The final part of this chapter has discussed the

arguments raised in *Nicklinson*. This discussion has incorporated the traditional conceptual arguments raised by the assisted dying debate. I then argued that these arguments have ignored how the practice of care, from professionals to family, can inform and result in a different understanding of vulnerability and the right to assist.

CHAPTER FOUR: HOW CAN AN ETHIC OF CARE APPROACH RECONCEPTUALISE A
LEGAL AND REGULATORY FRAMEWORK FOR ASSISTED DYING?

1. Introduction

This chapter will be divided by five different scenarios where an individual requires assistance to end their life. The first scenario discussed will be the individual who has both full mental and physical capacity. This scenario will be used to demonstrate the limits that a care-based approach takes to support claims for assistance. The second scenario discussed is where the individual has mental capacity but lacks the physical capacity to end their life. The discussion of this scenario will focus on a care-based approach to autonomy and will argue that this approach supports the legalisation of assisted suicide. This section will focus predominantly on the state's response to care. The third scenario discussed in this chapter concerns the individual who lacks both mental capacity and physical capacity. The paradigmatic example used in this section will be the patient in a MCS. This section will apply a care-based perspective on how to determine whether to withdraw treatment. This will rely on an evaluation and comparison of both the best interest and substituted judgment test respectively. Building on this analysis the fifth section of this chapter will discuss whether a care-based approach could regulate assisted dying for patients living with dementia. The final section will then discuss the role of the health care professional's assistance and also, ultimately, whether a care-based approach supports the claim to the right to assistance.

2. Full physical and mental capacity – the limits of a care-based ethic?

At this juncture where it is important to discuss the individual who has full physical and mental capacity as this scenario demonstrates the limits of a care-based approach in regulating assisted dying. Recently, there have been attempts in the Netherlands to widen legal frameworks concerning assisted dying. It has been suggested that new legislation should be introduced in order to extend assisted dying practices to those who feel they have

“completed life.”²³⁴ This attempted legislation is primarily aimed at those who are elderly and who feel that they cannot gain nor contribute anything more to life. An example of this scenario can be illustrated by Wijngaarden *et al*'s study into care at the end of life. One participant stated:

Look at the condition of those old ladies in the building opposite. Gaunt and half dead, pointlessly driven around in a wheelchair, it is simply horrible... In my eyes, it has nothing to do with being human anymore. They don't even know it, they just go through the process, and then suddenly ‘the black car’ arrives again. It is a stage of life, I simply don't want to go through.²³⁵

In this instance, the individual who has both physical and mental capacity would be entitled (if satisfying specific eligibility criteria) to some form of assistance to end their life, most likely a lethal injection. Because the individual in this scenario has the physical ability to end their life (obviously this is dependent on the physical health of each individual) there is a question concerning the moral reprehensibility of aiding an individual to die who can seemingly do this by themselves. Given this and having established that a care-based ethic would justify a regulatory framework for assisted dying premised on autonomous decision-making it would appear logical that this justification would also be applicable to those who feel they have “completed life.” The issue at hand is therefore how far a care ethic would legitimately support assistance and whether there is a limit to the moral reprehensibility of acts which purport to reflect caring attitudes.

Wijngaarden *et al* have argued that while the elderly value self-determination and autonomy they are also greatly influenced by feelings of sadness and loneliness. Those in

Wijngaarden's study were described as:

²³⁴ Wijngaarden *et al*, ‘Ready to give up on life: The lived experience of elderly people who feel life is completed and no longer worth living’ *Social Science and Medicine* 69 (2015) 257-264.

²³⁵ *ibid* 262.

[...] driven by a strong human desire to be visible, recognized, wanted, needed, valued, depended upon, or attended to by others. This desire illustrates the complex ambiguous tension in human life that, regardless of how independent a person might present himself, he is at the same time, a needy, vulnerable who depends heavily on others.

I argue that it is here where a care ethic approach to intersectionality is useful. If process-based autonomy is applied in this scenario the social construction of the “elder” identity can be realised (seemingly that they are undervalued and often ignored as members of society). If these feelings are the result of a societal response to the elderly then the solution to this does not appear to support a regulatory framework for assisted dying but rather a relocation of care and relationality into the public domain.

In response to this, and as discussed in chapter one, by incorporating a communitarian ethic for care and dependency I argue that assisted dying should not be legalised for those who have full physical and mental capacity. Instead we should facilitate good social care options. With this, the stigma of dependency which was often repeated in the participant’s responses can be broken down. As Sevenhuijsen argues²³⁶ the relocation of care into the public domain is beneficial for the quality of care in interpersonal relations and for the good of the society as a whole. Societal responsibility for care is a moral good and by placing it in the public domain, care can be received by more members of society. Therefore, when reconceptualising a framework for assisted dying, a structural perspective of the various relational limbs that influence the desire to end one’s life must be taken into account.

What a care-ethic provides is an argument to *why* individuals feel they have a “completed life” and suggests that a societal model of care is required. Therefore, a care-based analysis

²³⁶ S Sevenhuijsen, *Citizenship and the ethics of care* (n62).

does not support regulatory framework or assistance where the individual in question has both physical and mental capacity and has access to good quality care options.

Yet there will be scenarios where good quality and adequate care is not available. This then raises the question of whether assisted dying should be permitted when good quality care options do not exist or cannot be accessed. This relates to Tronto's principles of attentiveness and responsibility respectively. In application of Tronto's principled approach, being aware of the needs of the individual may result in an understanding of the feelings which cause an individual to believe they have "completed life." This is not necessarily unhelpful to a discussion of the regulation of assisted dying. However, it is the correlative principle of responsibility which poses an issue for a regulatory framework. As discussed in chapter one, the principle of responsibility is distinguished from the caring obligations which have traditionally been associated with gendered and traditional care-based roles. Because responsibility is not an obligation but rather an ambiguous response to the care-recipient's needs there is no negative duty (because of the restriction of the use of obligation) to prohibit the care-giver to partake in assisting the elderly individual to die. Therefore, if Tronto's principle of responsibility was incorporated into a regulatory framework, assisting the individual who feels as if they have "completed life" and do not have access to good care options would be acceptable. Yet as Sevenhuijsen notes, care is also the object of public opinion. Although a care ethic could support assistance for individuals who have full mental and physical capacity and lack other care options, care also reflects our societal identity.

It also concerns care as part of a politics of needs interpretation, as a dimension of cultural identity and as object of taste and opinion; care as a moral perspective, as a form of existential ethics and as a medium for building ties and commitment.²³⁷

²³⁷ S Sevenhuijsen, *Citizenship and the ethics of care* (n62).

In the most recent poll²³⁸ concerning the legalisation of assisted dying, only forty-six percent of the sample agreed that assisted dying should be legalised for those suffering from a ‘painful, incurable but NOT terminal illness.’ Comparatively, when considering assisted dying for those who were terminally ill, sixty-nine percent thought that assisted dying should be legalised in this instance. These statistics demonstrate that a societal response to assisted dying remains conservative in its eligibility criteria. I argue that if there is only a majority of the population in favour of assisted dying for those with a terminal illness and minority support for those who have a painful and incurable illness, collective societal view is that assisting an individual who has both physical and mental capacity (even if they lack care options) is morally reprehensible. As a result, I argue that there must be a negative obligation to not assist those where it would be morally reprehensible. In current society, it is likely that assisting individuals who do not have access to good care options to remedy a “completed life” is morally reprehensible. Such an act comes dangerously close to euthanasia practices as opposed to the practice of an assisted death.²³⁹

This section has demonstrated that a care-based ethic does not extend to assistance for those who have both mental capacity and physical capacity. Rather the limits of a care-based regulatory framework rely on a communitarian reflection of a societal response to the moral reprehensibility of certain acts.

3. Physical incapacity and mental capacity

This section will discuss how to regulate assisted dying for individuals who have mental capacity but are unable because of a physical disability to end their own life. For reasons discussed in chapter two, in re-establishing a regulatory framework for assisted dying the

²³⁸ UGov and Sunday Times Survey Results
<http://d25d2506sfb94s.cloudfront.net/cumulus_uploads/document/rpu120r18w/YG-Archives-Pol-ST-results-2906-010712.pdf> accessed 3rd August 17.

²³⁹ See further the discussion of Otlowski’s definitions in Chapter One.

suggested criteria will not be premised solely on a terminal diagnosis. In addition, having established in chapter two that autonomy underpins the DPP's guidance, in reconceptualising a framework for individuals like Mr Nicklinson, emphasis will be placed on a care-based approach to process-based autonomy.

I argue that a framework that is underpinned by autonomy should be inclusive of Friedman's model of critical reflection. This care-based approach takes a step further than ensuring a 'voluntary, clear, settled and informed decision to commit suicide.' By contrast, Friedman's approach would require an evaluation of the cognitive, emotional, historical preferences and desires and relationships of the individual who requests assistance. In contrast to Biggs's approach which infer that isolated decisions secure a sufficient level of autonomy I argue that Friedman's process-based approach places a higher-level of emphasis on the decision-maker. This provides them with the opportunity to reflect *appropriately* on the gravity of their decision. I argue that an important benefit of this approach is that the decision-maker can be supported in working through these different values. This is not to say that this support determines the individual's answer and thus "pressurises" them to either end or continue their life. Rather, this approach provides a framework for enabling the realities of how we make decisions in every-day life. These decisions are relationally informed, interdependent on various factors and are not normatively dictated. Moreover, by ensuring autonomy is based on this criterion we can avoid making decisions premised on the social construction of identity. This is an important as the risk of stereotyping disability has been overlooked by those who are concerned with increasing the vulnerability of those who are disabled. Friedman's criteria could answer the concerns of these critics. Friedman's theory requires a comprehensive analysis of one's own values and identity.²⁴⁰ Often, we do not reflect on our own values which express our own intersectional identities. Thus, especially for those

²⁴⁰ M Friedman, *Autonomy, Gender, Politics* (n99).

individuals *who* are labelled as disabled, considering the label of “disabled” encourages a deeper reflection as part of the autonomy criteria. Therefore, in ensuring that an autonomous decision has been made the factors in Friedman’s critical reflection should be set out as a basic criterion.

The question of normativity also applies to what type of experience should inform an autonomous decision. At first blush, it may appear that autonomous decision-making should be premised on episodic concerns or experiences (those that define our values and beliefs). However, as per the concept of unbearable suffering which has informed much discussion surrounding potential UK legislation I argue that a care-based approach is inclusive of programmatic concerns those experiences of day-to-day life. If we only premise decisions on deeper values and beliefs we ignore the very realities of every-day life which, arguably, is at the heart of those like Mr Nicklinson. Therefore, when considering the criteria that make up Friedman’s critical reflection, a consideration of both programmatic and episodic experiences should be given equal evaluative weight.

The result of a process-based version of decision-making results in a higher standard of autonomy but with this, is the ability to support decision-making and therefore reflect the realities and benefits of the decision-making process. Despite this, safeguards are still required to stabilise the suggested criteria which will be discussed in the following paragraphs.

Safeguarding the vulnerable

In *Nicklinson*, judicial reasoning focussed substantially on protecting the vulnerable. As discussed in chapter three, the vulnerable were described as those who were a burden on their care providers and those who felt pressured to end their life. Specifically, the elderly and the disabled were categorised in this light. Lord Kerr and Lady Hale noted that this line of argument actually ignores the vulnerability of individuals who are disabled but require

assistance to end their life. I argue that creating regulatory safeguards in response to the concept of vulnerability requires an appropriate understanding of what vulnerability means and how it can be managed. This understanding requires a wider perspective of how different areas of assisted dying regulation are interconnected to vulnerability.

As discussed in chapter one, vulnerability can be caused by either biological or societal sources of misfortune or catastrophe. For the purpose of assisted dying I draw on Dodds's discussion of dependency, care and vulnerability as this reflects the regulatory safeguards in response to the risk of a pressurised death.²⁴¹ Dodds's argues that ignoring the causes of context specific vulnerability (situational vulnerability) which derives from social, political, economic, or environmental factors engenders what is known as pathogenic vulnerability. Pathogenic vulnerability are those vulnerabilities, as a sub-set of situational vulnerability which should have been eradicated by society. In turn, Dodds's argues that often, pathogenic vulnerability arises out of public policy which draws on an ideal of autonomy. This ideal cannot be achieved by those who are deemed to be situationally vulnerable and as such remain dependent on care. For example Mr Nicklinson could only end his life through starvation. These individuals cannot achieve the level of autonomy that legal frameworks and state policy deem appropriate. These individuals are reliant on care and become increasingly vulnerable.

Dodds's offers a solution to this issue by suggesting that we recognise the value of relational autonomy developed through interpersonal and social relationships. Indeed, this illustrates the benefits that Meyer and Friedman's respective process-based approaches to autonomy offer in respect to regulating assisted dying. This highlights two responses to the arguments concerning vulnerability and safeguards. Firstly, I argue that dependency on another individual for care does not necessarily mean they are vulnerable. The relational dynamic that

²⁴¹ S Dodds, 'Dependence, Care and Vulnerability' in C Mackenzie *et al*, *Vulnerability; New Essays in Ethics and Feminist Philosophy* (OUP 2004).

exists could support the autonomy of individuals like Mr Nicklinson. Secondly, though some biological vulnerabilities do exist I argue that these easily become situational if not pathogenic because of how the state facilitates care. If the state does not take responsibility for care and dependency then an inference can be made that there is a heightened sense of vulnerability because the care-based options (either provided directly by the state or facilitated by the state) are unavailable.

For example, the inability to discuss assisted dying as an end of life option with health and social care professionals heightens the vulnerability of specific groups such as the elderly or disabled. By including this discussion in a regulatory framework, we do not gloss over the realities of the individual who requests assistance. This discussion can ensure that the individual understands what an assisted death means and can compare this to other care options. Without this support, the individual could be vulnerable to pressure from others and misinformation. Therefore, when we define vulnerability as a precursor to how we provide appropriate regulatory safeguards it is important to recognise that it is not just the physical or age-related conditions of individuals that determine what vulnerability is. Rather, an understanding of vulnerability is inextricably linked to societal influence and response to the individual who requests assistance. The benefits of a care-based approach in this instance is that it looks at the structural emphasis on vulnerabilities rather than what is often over-emphasised in assisted dying arguments as the one-on-one “burden.”

Building on the above discussion, safeguarding the vulnerable is often associated with the concept of slippery slopes. As previously discussed in chapter three both the logical and empirical arguments do offer a standard by which assisted dying practices could be measured. However, what a care-ethic does is highlight another value by which a slippery slope could be measured. This is the availability and access to quality care in the jurisdiction where the individual who requests assistance lives. Thus when we assess the seriousness of

vulnerabilities and the likelihood that these would engender pressure on the individual regulation must also look to how social care policy and care-labour policies affect vulnerability. There is then scope to compare these policies within euthanasia practices in other jurisdictions to model a regulatory safeguard which turns on how (a lack of) care can affect the discussion of safeguarding of those who are vulnerable.

This section has highlighted the inextricable link between how we can use the concept of care to respond to vulnerability and how this affects the application of appropriate safeguards.

Indeed, I have argued that a care-based approach to process-based autonomy supports a legal framework which establishes a critical reflection of both programmatic and episodic experiences and values. I argue that this approach applies a high threshold for autonomous decision-making but also allows the individual in this scenario to be supported through this decision-making process in reflection of every-day decision-making.

4. The individual who lacks both mental capacity and physical capacity

The scenario discussed in this section reflects the individual who is in a MCS, like the experiences of Mr Briggs and Mr James already discussed in this thesis. This section will therefore focus on a care ethic response in determining whether treatment should be withdrawn. Although traditionally, withdrawal of treatment has not been defined as assisting an individual to die, I argue that withdrawal does come within the definition of assisted dying and therefore should be discussed in light of this. Therefore, a substituted judgment or a best interest test will be compared and evaluated utilising the contributions made to the care-based literature.

Substituted judgment test

As discussed previously in this thesis, a substituted judgment test seeks to establish what the individual who lacks capacity would have wanted. With Article 12 of the UN Convention on the Rights of Persons with Disabilities 2006 (UN CRPD) advocating a substituted judgment

test and with increasing case law emphasising its use within a best interest test it is important that an evaluation of this test from a care-based approach is undertaken. A substituted judgment approach then typically relies on sourcing this information from family and friends who are *presumed* to know the wishes and feelings of the individual in question. This draws parallels with Tronto's principled care-based approach which is focussed on being attentive to the needs of the individual. This is because Tronto's theory emphasises a care-based response to the specific need of the individual in question. As Walker has stated, the cared for and the carer's stories intersect and become a story of dialogue rather than an abstract system of obligations.²⁴² This is also supported by Noddings's care-based approach which argues that we should be 'responsive to the individual's needs.'²⁴³ Thus, like Tronto's principle of responsibility, it appears that those who care for or are in caring relationships with the individual who lacks capacity could provide an understanding of what the individual would have wanted. On this understanding then, care is defined as responding to the needs of the individual rather than what would be in their best interests. In applying a care-based approach to the withdrawal of treatment I argue that a substituted judgment would be made. Building on this (and as discussed in previous chapters), whether a substituted judgment made by carers (typically family and friends in this instance) is accurate has been questioned widely. Therefore, a discussion about who is the appropriate person to make a substituted judgment is required.

What relationship means you can make a substituted judgment test?

Under a gendered care-based approach it would appear that those who are entitled to make a substituted judgment are members of nuclear and biogenetically-linked families. Typically,

²⁴² M U Walker, *Moral Understandings: A Feminist Study in Ethics* (Routledge, 1997).

²⁴³ N Noddings, *Caring: A relational approach to ethics and moral education* (2nd edn, Univeristy of California Press, 2013)

this approach has been reflected in the best interest approaches taken by the courts.²⁴⁴

However, applying Weston's definition of family broadens the scope of which individuals should be included in making a substituted judgment. If family is defined as providing sentiment, emotional support and financial aid a wider spectrum of relationships can be included. The benefits of this approach means that not only does the law reflect the plurality of relationships that exist in society but by gaining views from a wider group of individuals it is likely that a more representative view of what the individual would have wanted will be achieved.

Substituted judgments made by other than just the family

Having established that a care-based reconceptualisation of family can enhance a substituted judgment there still remains an issue of whether a substituted judgment test should include relationships which fall outside the family bracket. This was exactly the case in *Briggs*.

Although emphasis was placed on Mr Briggs wife's views his wider family, friends and colleagues had also provided evidence. From a care-based perspective then, a question must be asked of what type of care-based relationship constitutes the ability to submit evidence under a substituted judgment test. Cooper's investigation²⁴⁵ into the practices of care provides an interesting application to the substituted judgment. As care does not have to be deep and meaningful but rather it can be superficial or short-term, this provides an additional underdeveloped layer to the substituted judgment test. For example, the individual who had a conversation with the individual previous to having been in a MCS on his train commute to work every day is considered as practicing care. It is likely that we would not know how much this practice of care meant to the individual in MCS. This then raises the question of whether that "commuting friendship" should be considered as contributing to a substituted

²⁴⁴ See further; *Briggs* (n10), *Aintree* (n9), *United Lincolnshire NHS Trust v N* (n192).

²⁴⁵ D Cooper, 'Caring for sex and the power of attentive action: Governance, drama and conflict in building a queer feminist bathhouse' (2009) *Signs* 35.

judgment test. Equally, the individual in MCS may have friends who he regularly meets with but would not necessarily believe they could determine what the individual would have wanted. In comparison, the individual in MCS may have friends who he communicates rarely with but nonetheless their friendship is one that means he would trust them to make a substituted judgment on his behalf. I argue that Cooper's stress on considering the plurality of caring practices and relationships illustrates a major disadvantage of the substituted judgment test. This is because if a substituted judgment is going to be accurate it must reflect the views of those beyond familial relationships. Yet when we seek to use the relationships outside of the family what is found is a plurality of relationships where care is practiced in different ways. How these relationships are quantified and applied in a substituted judgment scenario is difficult to conceptualise. Pragmatically, a true reflection of the relational dynamics connected the individual who lacks capacity is at the very least, difficult to achieve.

However, a relational care-based approach could alleviate the issues raised here.

Traditionally, where relational dynamics have come before the courts, a property rights entitlement has often been applied. As Nedelsky notes, instead of focussing on establishing or maintaining positive relational interaction, the courts have seen familial ties as an entitlement to a relationship. This highlights the importance of analysing the individual who lacks capacity's everyday life dynamic through relational interaction. By using this as a tool within the substituted judgment test we could potentially view the different formal and informal, public and private structures and relationships that inform what that individual would have wanted. As Nedelsky has argues:

Intimate relations, such as spousal relationships, are shaped by societal structures of relationship such as those formally shaped by family law as well as powerful norms of gender roles. These structures will be shaped by patterns of economic relationships, such as employers' preference for hiring men in high paying jobs, expectations that

authority should be exercised by men over women, and governmental policies that ensure the availability of (overwhelmingly female) child care workers from abroad who will accept low pay. The availability of such workers arises from long-standing relations of global economic inequality. Each set of relations is nested in the next, and all interact with each other. Relational selves shape and are shaped by all interactions.²⁴⁶

From this relational perspective, I argue that a substituted judgment test which evaluates the value of relationships provide an important contribution to understanding what the individual would have wanted. This approach reflects the different formal and informal, political, economic and other influencing factors which can determine the type of relationship and practice of care that exist in our social networks.

However, as discussed previously in this thesis, much criticism of the substituted judgment test is the potential risk that those providing evidence get it wrong. This could potentially lead to the unintended death of the individual or equally the continuation of life which would not be wanted. However, I argue that no law or legal mechanism is infallible and as such a substituted judgment test should not be ignored on this basis. Instead, I argue that an acknowledgment that a substituted judgment may produce an “incorrect” result is important and that a baseline of allowance for incorrect judgments must be set.

I argue that a care-based approach to a substituted judgment must place relationality at its core. Without doing so there is a risk that we rely on traditional relationships, which could be negative. Yet by using the potential multiple relationships that exist in the individual’s life a substituted judgment test can be used to reflect a more representative view of what the individual would have wanted.

²⁴⁶ J Nedelsky, *Law’s Relations; A Relational Theory of Self, Autonomy and Law* (OUP 2011) 31.

The best interest test

As discussed previously in this thesis, the best interest test is informed by both an objective and subjective analysis of competing interests to support the welfare of the individual who lacks both mental and physical capacity. The best interest test therefore is inclusive of a substituted judgment. In recent years though it has been argued that this should take a majority emphasis it is still not definitive of the outcome of a best interest test. Therefore the discussion concerning substituted judgment test is also applicable to an overall analysis of the best interest test. The following paragraphs will first discuss a care-based approach to the best interest principle.

I argue that the best interest principle is typically perceived as continuing, in a somewhat similar light to the substituted judgment, to focus on the individual who lacks capacity. In applying a care-based ethic to the best interest test there are two different approaches to take. If the best interest test is understood as attempting to achieve the optimum welfare interest, then a traditional care-based ethic would be applied. It is here where there is a risk where a maternal-based care-ethic could be applied. For example, Noddings's 'engrossment' in the individual who lacks capacity is over-involved. This is because of the role the care-provider has. They become over-responsible for the interest of the individual, which they deem as best. On the other hand, if Tronto's principled approach is applied to a best interest test, one can easily revert back to a substituted judgment focus. The principles of attentiveness and responsibility respectively are both subjectively interpreted by the care-provider. Therefore, a care-based application to the best interest test is not necessarily an easy fit and has the potential to take two extremes rather than achieve the purpose of the balance required. However, where a care-ethic is helpful to a reconceptualisation of the best interest test is the relational qualities that exist within care-based ethics. I argue that by focussing on the practice of care the different depths of relational caring practices we can understand the

embodied individual who is (potentially) influenced by the interpersonal and structural contexts that shape their everyday life. This contextual relationship understood from the practice of care establishes a balance between a maternal model of care ethic and a focus on the responsiveness of the individual who lacks capacity. These relational qualities can be applied to all those care actors who contribute to a best interest test.

Often in the withdrawal of treatment scenario the health care professional is involved in contributing to what is in the best interest of the individual who lacks capacity. This contribution is also equally applicable to the social care professional and any other individual who has an interest in the individual who lack capacity's welfare. Therefore, under a care-based understanding for the care professional (either health or social) it is the relationship that dictates what information is required to inform a best interest analysis.

In this instance, as established in chapter one, the patient-professional relationship should be regulated by Tronto's care-based principled approach. I argue that Tronto's principle of competency takes an important precedent and should limit the input of the health care professional. Though in the withdrawal of treatment scenarios the health care professional may have provided treatment over a long period of time this does not satisfy the health care professional offering more than their professional opinion only. Their relationship is one which is defined by professional relational boundaries and as such this means their knowledge of what is in the best interest of the individual who lacks capacity is strictly limited to their professional knowledge.

An interesting relational dynamic in the best interest scenario is that of the social care professional. Typically, in the withdrawal of treatment scenario, the social care professional will provide daily care to the patient in a MCS often in a hospice or care home. Because a diagnosis of a MCS means that the patient has the potential to interact with others or the environment around them, the social care professional could be said to have a deeper level of

understanding of the patient than just providing or assessing the required “treatment.” This claim is obviously dependent on the spectrum of interaction and communication that the patient in a MCS demonstrates. Given that this interaction will involve displays of emotion from the individual who lacks capacity it raises the question of whether the care professional has the obligation to discuss the interaction and communications of the patient who lacks capacity despite having a professional relationship of care. This *occurred* in *W v M [An Adult Patient]*.²⁴⁷ Though Baker J placed an emphasis on the preservation of life, his use of the social carer’s opinion was important to a care-based analysis.

Carers with extended and recent experience of the patient will thus be better equipped at interpreting that behaviour. In this case, in contrast with the family members, nearly all of the care staff at the nursing home who were called to give evidence have had extensive and recent experience of M’s behaviour. Accordingly, and having heard them in the witness box, I find that I can give considerable weight to their evidence as to M’s behaviour, fortified by the fact that these interpretations have been substantially corroborated by the formal assessments carried out using the SMART and WHIM processes.²⁴⁸

I argue that under a care-based analysis, Tronto’s principled approach should still be applied but caution must be taken that when the individual in a MCS demonstrates feelings of enjoyment or unhappiness that this is a *perceived* understanding of the individual’s wishes and feelings. Importantly, this understanding must only derive from the professional interaction that the carer has with the patient in MCS. Interestingly a comparison can be made to the social care professionals’ role when caring for an individual in PVS. The individual in PVS will not respond to their environment in any way and as such the health and social care professional’s role is their view to the care they administer. Thus, although

²⁴⁷[2011] EWHC 2443 (Fam).

²⁴⁸ *ibid* [210].

caring for an individual in PVS or MCS may be distressing for the health and social professional respectively, their professional role outweighs any emotional context that may inform a best interest analysis.

Thus far this section has discussed a best interest analysis solely from the perspective of the patient who lacks capacity. As section 4(c) of the MCA states, the best interest test is required to take into account any other factors that would be likely to influence the decision of the individual who lacked capacity.²⁴⁹ Though it may appear unusual to suggest a different perspective, a care-based analysis offers insight into the other factors that may well support a best interest analysis apart from a direct focus on the individual who lacks capacity.

Building on the relational context that the substituted judgment test and best interest test respectively rely upon it is arguable that these very relationships can be a determining factor in the best interest test. For example, in *Bland*, the Lords' reasoning reflected the emotional context of living with a brother and child who was in PVS and a 'living death.' For Mr Bland's family, his physical existence placed a barrier to grieve appropriately for the "loss" of their family member. Though the decision in *Bland* was before the introduction of the Mental Capacity Act 2005 the recognition of the relational contexts that existed and the effects of Mr Bland's PVS had on these relationships was apparent. I argue that this was also reflected in *Briggs* where Charles J recognised the impact of Briggs's condition on his family, namely his young child. In the evidence submitted, it was stated that Mr Briggs had previously wished that if he were in the position that had befallen him that he would not want his child to visit him. Mr Briggs felt it was inappropriate for children to see adults in such a condition. It is here where using a relational paradigm, such as those suggested by

²⁴⁹MCA.

Nedelsky²⁵⁰ that the relational nature of every day decision making can be investigated. This approach reflects the centrality of care and support that these relationships are part of. By making best interest decisions which are inclusive of the possibility of prioritising those who have a relationship with the individual who lacks capacity we achieve the very purpose of the best interest test. The purpose being that the impact on our relationships with other individuals can be a reflection of how we make decisions in everyday life, and thus must reflect the decision of whether to withdraw treatment from individuals who lack capacity also.

Should we consider death as an option?

The best interest test is firmly grounded by the presumption of the preservation of life,²⁵¹ and as such the question of whether either a substituted judgment or a best interest test respectively should view death as an option rather than a consequence is an important issue to raise. As I have argued in the previous chapter this is demonstrated by Charles J's reasoning in *Briggs*,

On that approach and analysis, the court would not be taking into account a desire to bring about Mr Briggs' death albeit that if he had capacity so could determine what treatment he had, as a matter of law, he could be motivated by a desire to die or express himself in that way, and he may well not have analysed the issue by reference to that question and the doctrine of double effect.²⁵²

In an analysis of Noddings's care-based ethic there is nothing to suggest that her ethic of care would support the option of choosing death. It appears that Noddings's emphasis on the contextualised circumstance of caring ignores the relationship between care and reflecting an autonomous choice to end life. A theory that is premised on traditional caring paradigms is

²⁵⁰ J Nedelsky, *Law's Relations; A Relational Theory of Self, Autonomy and Law* (n243).

²⁵¹ MCA.

²⁵² *Briggs* (n10) [94].

one that is likely to preserve life at all costs rather than seek to understand the needs of the individual. This is where Tronto's approach appeals to the modern-day dilemmas of withdrawal of treatment issues. Tronto's principle of attentiveness points to being responsive to the individual's need. If this need is that the individual would want to die, which is inclusive of the withdrawal of treatment process, then under Tronto's principled approach the option of choosing death would be supported.

However, as Sevenhuijsen has argued, care can be relocated onto the public stage and can be used as a democratic process. Therefore, when we discuss whether to include death within an analysis of the withdrawal of treatment an understanding of what this means for a societal response to care is important. The practice of care in the private domain can integrate with public agency and reflect taste, opinion and cultural identity connected to the practice of care. Thus, in the context of the withdrawal of treatment, using the concept of care in both the public and private domain we can view choosing death as both a private decision on behalf of the individual who lacks capacity, and also how such decisions are a reflection of societal values and attitudes.

In reconceptualising a regulatory framework for individuals who lack both physical and mental capacity I argue that a best interest test should be utilised above solely using a substituted judgment. This is because the use of a substituted judgment does, in comparison to a best interest test, have serious issues with the ability to achieve an accurate and reliable understanding of what the individual would have wanted. A best interest test can be inclusive of the effects on those who are in caring relationships with the individual who lacks capacity. Yet this does not mean that the substituted judgment test as part of the best interest test should be ignored. I argue that the substituted judgment test should broaden the scope of relational contributions but the type of information provided should reflect the relational dynamic related in that context. The best interest test provides the necessary checks and

balances that a substituted judgment lacks and includes a wide range of evidential sources. Thus, in a reconceptualisation of determining when to withdraw treatment I argue that a best interest analysis should be taken. Yet this is with the understanding of how relationships and the practice of care can influence both the informal and formal structures that determine the views of others and what would be in the best interest of the individual who lacks capacity.

5. Can we assist dementia patients to die?

Having established how to regulate assisted dying for the individual who lacks mental and physical capacity there is scope to apply this framework to the complex scenario that surrounds individuals who have been diagnosed with dementia. This analysis evaluates two different dementia scenarios. The first scenario is of the patient who exhibits symptoms of dementia, typically a loss of capacity, but when they had capacity they wished that when they reached such a stage they wanted their life to end. In response to this scenario, what would be required is some form of advance directive. Currently, the MCA does include advance directives but these are not for the purpose of requesting assistance to die via active means. The second scenario is where the individual is living with the later stages of dementia and because of this are more likely to experience physical illnesses such as bed sores or pneumonia. In this instance, often, treatment will be withdrawn or do not resuscitate orders will be put in place. This is not to say that the treatment would be futile but that this provides an “opportunity” to prevent the continuing experience of living with dementia.

In response to the first scenario and what appears to be an advance directive is a care-based understanding of process-based autonomy. Process-based autonomy has been discussed in the first chapter of this thesis. However, for the purpose of the individual who is living with dementia, emphasis must be placed on the contextualisation of experience which is stressed by a care ethic. I argue that the transition of care ethics from a maternal and traditional model to a political model has maintained an emphasis on the unique context of the scenario at

hand, with the ability to be flexible in response to the practice of care. Although process-based autonomy may support an advance directive that regulates assisted dying for the individual that lives with dementia, I argue that a care-based ethic also focuses on the current experiences of the individual living with the symptoms of dementia. This means that the current scenario in which care is practiced also directs decision-making. Indeed, there is nothing in Tronto's care ethic which suggests that the principle of attentiveness prioritises previous wishes and feelings above current wishes and feelings. In turn, I argue that a care-based ethic, in line with the emphasis on the unique context of individual circumstances, would focus on the current needs, wishes and feelings of the individual who is living with dementia. Therefore an autonomous precedent request for assistance to die prior to a loss of capacity could not be regulated by a care-based legal framework. However, where the patient who is living with dementia is perceived to be suffering (for example her dementia causes him or her to demonstrate unhappy emotions) there is scope to consider assistance to die from a care-based perspective.

If the principle of attentiveness (and equally Noddings's principle of responsiveness) is applied to the individual who is living with negative symptoms of dementia these principles could be used to determine the individual's want to end their life. In this scenario, a lethal injection may be given to the individual in order to end their life. However, despite an "unhappy" existence or experience of suffering it is questionable whether we should assist an individual to die. Arguably, as this chapter has demonstrated, a care-based ethic would support assistance for those individuals who do have capacity but lack the physical ability to end their lives themselves. Therefore, one could argue that the recognition of suffering which cannot be ameliorated also supports assistance for those suffering with the symptoms of dementia. Yet I argue that this comes very close to the practice of active euthanasia; that

without capacity and still with some physical ability assisting this individual to die remains morally reprehensible.

In contrast, the withdrawal of treatment from a patient due to the physical symptoms caused by dementia demonstrates the moral distinction between the above scenario and the practice of active euthanasia and assistance conceptualised as withdrawing treatment. In these scenarios I argue that the withdrawal of treatment is less morally reprehensible than administering a lethal dose of medication for the purpose of ending the individual's own life. The practice of passive euthanasia in this scenario does highlight a difference between societal responses to the practice of care. As noted in chapter three, I argue that the withdrawal of treatment (whether this is deemed as care or treatment) is permissible for individuals living with dementia. This is not because, by contrast, active euthanasia is perceived to be causing death but passive euthanasia (or the withdrawal of treatment) is perceived as letting the individual die: rather it is premised on how we conceptualise active euthanasia in response to the practice of care in our current society. By using a care ethic to solve this dilemma we can apply a care ethic to the social policy that surrounds assisted dying regulation.²⁵³ As Sevenhuijsen has argued, care is the object of taste, opinion and cultural identity and therefore the practice and regulation of care will always reflect this societal response.

In current society then, I argue that public opinion still believes there is a marked difference in the moral reprehensibility between active and passive euthanasia. Such attitudes shape our response to what practices therefore determine care. As such, whether or not there is a logical distinction between active or passive euthanasia, if active euthanasia is distasteful to society's understanding of care it does come within a reconceptualised regulatory framework. Thus if we are to take care as a democratic practice which reflects the regulation of assisted dying it

²⁵³ For a discussion of this see further; S Sevenhuijsen, 'The Place of Care: The Relevance of the Feminist Ethic of Care for Social Policy' (2003) *Feminist Theory* 4(2) 179 -197.

will also reflect public opinion on the practice of care – despite this possibly leading to illogical regulatory principles. Having established the dementia’s place in the assisted dying context, it is also important to discuss how a care-based ethic would reconceptualise the role of the health care professional in administering assistance.

6. Regulating Assistance – The role of the healthcare professional

The role of the care professional is important for two preliminary reasons. Firstly, the health care professional has the appropriate knowledge and skills to ensure that an assisted death is safe and as painless as possible. As discussed in chapter two, the case of Kay Gilderdale provides a pertinent example of the consequences when there is a lack of professional guidance in response to the individual who requests assistance to end their life.²⁵⁴ Secondly, it is likely that, for the individual who requests assistance, the decision to end one’s life is the result of a condition which involves the care of a health care professional. This is not to say that the health or social care professional must be present but it is important that the individual who requests assistance is inclusive of the provision of advice and expertise on assisted dying.

Is discussing assisted dying assistance?

I question whether the care professional is providing competent care if they are prevented from discussing the option of assisted dying and as such this leads to the question of whether a “discussion” of assisted dying can be determined as assistance. The consequences of shutting down any discussion concerning assisted dying, the healthcare professional fails to take a full account of the individual’s experiences and desires. The result of this is that the healthy professional-patient relationship is potentially eroded because of the “elephant in the room” that cannot be openly and freely discussed. It is important to note, however, the

²⁵⁴ See further; The Guardian, ‘Kay Gilderdale: A devoted mother’ <<https://www.theguardian.com/uk/2010/jan/25/kay-gilderdale-devoted-mother>> accessed 1 March 2017.

difference between discussion and advice. I would argue that discussion is a dialogue between individuals where an exchange or expression of feelings and thoughts are given. In contrast, I argue that advice is defined as specific guidance. In application to the individual who requests assistance, I argue that discussing that the individual in question would want to end their life is not assistance if this discussion did not concern advice about how to end one's own life. This approach differs from the BMA's guidance on "shutting down" questions as though the health care professional is likely to note the illegality of assisted dying, and therefore the reasons behind such a choice and the context it exists in is important to discuss with regard to patient wellbeing.

Moreover, I argue that the inability to discuss assisted dying as an end of life option with health and social care professionals heightens the vulnerability of specific groups such as the elderly or disabled. By including this discussion in a regulatory framework we do not gloss over the realities of individual experience. This discussion can ensure that the individual understands what an assisted death means and can compare this to other care options.

Without this support, the individual could be vulnerable to pressure from others and rely on inaccurate information. Therefore, when we define vulnerability as a precursor to how we provide appropriate regulatory safeguards it is important to recognise that it is not just the physical or age-related conditions of individuals that determine what vulnerability is. I argue that this reflects Dodds's definition of situational responsibility as the health care professional is part of a societal response to vulnerability. If an understanding of vulnerability is inextricably linked to societal influence and response to the individual who requests assistance then the health care professional has a responsibility to reduce the situational vulnerabilities associated with the individual who requests assistance.

Therefore, at a very minimum, assisted dying regulation must include a framework which allows health and social care professionals to discuss an assisted death as part of how the

individual in question contemplates their values and wishes. Building on this, I argue that assistance provided by the health care professional is qualified by the facilitation of how to end one's own life will be discussed in the following paragraphs.

What type of assistance – prescription or lethal dose?

Discussions regarding the type of assistance offered by the healthcare professional has often concerned a doctor administering a lethal dose of medication to the dying individual.²⁵⁵

However, the type of assistance that the health and social care professional can provide is variable. For example, assistance does not necessarily have to be an “immediate” lethal dose of medication administered at a specialised clinic for the very purpose of assisted dying.

Instead care professionals can facilitate assistance in a variety of ways. For example, as is the case in the US state of Oregon, the healthcare professional can provide assistance by providing a prescription of a lethal dose of medication. This is kept by the dying individual for a time when they feel it is necessary to end their life.²⁵⁶ Or indeed a social care professional can provide assistance by providing physical and emotional care labour when travelling to a clinic or in the preparation for an assisted death. Though one must make a distinction between medical care and social care pertinent to each role, these brief examples highlights that a regulatory framework for assisted dying must reflect the multiple ways assistance can be provided by the health and social care professional.

Importantly, in arguing that the care professional should provide assistance for assisted dying as part of a regulatory framework raises the issue of conscientious objection. Conscientious objection is defined as opting out of providing a particular type of care practice because of the individual's personal beliefs and values (as long as these values do not result in direct discrimination of the individual you are treating).²⁵⁷ By regulating the health and social care

²⁵⁵ *ibid.*

²⁵⁶ See further The Death with Dignity Act (Oregon) 1997.

²⁵⁷ GMC, *Good Medical Practice* (2013) (n125)

professional's role in this way, assisted dying is perceived like any other care option at the end of life rather than an act which is deemed as an elevated practice of care. Therefore, I suggest that assistance should be provided by a health and/or social care professional. However, by requiring the provision of assistance of health and social care professionals there is the potential for health and social care professionals to use their position to endanger vulnerable individuals. This potential risk is heightened by the killings of at least 215 patients by Harold Shipman who was a registered doctor and carried out these murders via his role as a General Practitioner.²⁵⁸ This then led to an extensive enquiry led by Dame Janet Smith which highlighted the regulatory flaws surrounding GMC standards, availability of drugs and the role of the coroner. Therefore, when we consider the provision of assistance by the health care provider we must include the necessary regulatory safeguards to ensure that health care professionals act within the bounds of their professional and legal conduct.

It is therefore pertinent to discuss whether requiring health care professionals to provide assistance to end the individual's life changes the role of the health care professional conceptually. Typically, health care professionals, not least doctors, were seen as gatekeepers to good health or care.²⁵⁹ However, if medical diagnosis is not part of a valid criterion for an assisted dying framework this suggests that health care professionals are facilitators. I argue that the benefit of this approach is that death is not over-medicalised and inextricably linked to medical diagnosis or symptoms but rather grounded in the realities influencing the decision to end one's own life. The consequences of this for health care providers is two-fold. Firstly, this may deter if not alter the reasoning of those who enter into the healthcare profession and secondly, the issue of conscientious objection also arises. In a similar light to Tronto's

²⁵⁸ N Bunyan, 'The Killing Fields of Harold Shipman' (2001) *The Telegraph* <<http://www.telegraph.co.uk/culture/4724155/The-Killing-Fields-of-Harold-Shipman.html>> accessed 01 Aug 2017.

²⁵⁹ K Veitch, *The Jurisdiction of Medical Law* (Ashgate 2007).

principle of responsibility, I argue that a care-based approach reflects the flexibility in how we respond to legitimate requests for assistance. In response to the first point highlighted, I argue that a regulatory framework which requires health care professionals to facilitate assisted dying could operate, like in other jurisdictions such as Switzerland, in separate clinics or with dedicated practitioners whose role is solely connected to assist dying. This means that the model of healthcare provision can be separated from ensuring continued quality of life. Secondly, I argue that if assistance provided by health care professionals is somewhat separated from a general healthcare model it is not beyond a reconceptualisation of regulation to incorporate an allowance for conscientious objection. This section has argued that the health care professional should provide assistance because of their knowledge and expertise and because they also are inevitably part of the individual's experiences. This is not to say that health care professionals are forced to assist but that a new model of assistance could be established within a framework which is separate from the traditional model of health care provision. Having established who should assist the following section will discuss whether a care-based ethic establishes a right to assistance.

7. Is there a right to assistance?

The DPP's policy states that professional carers will be prosecuted if they assist in the death of another. This illustrates that the right to assistance exists only in the private domain. Currently then, this right seems to point towards assisting suicide in another jurisdiction akin to the case of Daniel James. In this scenario, the assistance provided to help is overwhelmingly characterised as an emotionally influenced practice of care with this practice only existing in the private domain.

Under this analysis one can argue that there is a right to assistance formulated as either a liberty right or a right to non-interference and has also been considered as welfare right.

However, applying a care-based analysis I argue that a liberty right or right to non-

interference does not incorporate a full account of process-based autonomy. This is because it ignores both the relational aspects that are part of autonomous decision-making and the importance of autonomy within the public rather than private domains. I therefore argue that a care-based approach supports a welfare-based understanding concerning the right to assistance. A welfare-based approach is most commonly associated with Ronald Dworkin and draws parallels with Article 3 of the ECHR. Yet arguments based on a welfare approach aptly illustrate why assistance would not be considered a right under a care-based perspective. This is because underpinning each rights-based justification is a status-based approach. As discussed in chapter one, if a right is justified by a status-based approach it suggests that there is something innate and natural about the human being to which the right is attached to. Though this may support maternal paradigms of care-based ethics as discussed throughout this thesis, the importance of a non-normative identity framework concerning care is integral if it is to be used on a legal and political platform. Instead, by justifying assistance as instrumentally valuable, a right can be established. Therefore under a care-based analysis assistance is only justified as a right if it reflects the different layers of interpersonal relationships and is supportive of quality care and positive interpersonal private relationships. As such, a right to assistance is only morally valuable because it supports the practice of care. Under this analysis, the state has an obligation to facilitate the positive interactional relationship.

8. Summary

This chapter has built on the discussions developed in previous chapters in this thesis and has created a regulatory framework concerning three paradigmatic scenarios concerning assisted dying. The first section has argued that the individual who has mental capacity but lacks physical capacity should be entitled to assistance to end their life. This is justified by a care-based understanding of process-based autonomy deriving from Meyer and Friedman's

respective theories. I then argued that this produces a higher standard of autonomy than has been suggested in previous legislative bills. Included in this section was a discussion of vulnerability and how a situational and pathogenic approach can establish a better understanding of the structural influence on vulnerability care and assistance. Using this analysis, it was also demonstrated how vulnerability can supplement a slippery slope analysis as a regulatory tool. From this position a comparison was made to the scenario where the individual who has both physical and mental capacity but wishes to end their life. In response, a care-based application would not support this request for assistance. In turn, I argued that a care-based ethic would focus on the societal and structural issues that influence the want to end their life. Therefore, the limits of a care-ethic appear to be premised on a response to suffering. The second part of this chapter then focussed on the final individual who requests assistance, where the individual lacks physical and mental capacity. The outcome of this analysis then focussed on a comparative analysis between a substituted judgement and best interest test. The discussion of a substituted judgement defined the relational contribution and reliance on relational dynamics and demonstrated how a substituted judgement test, although having its merits, must be used with caution due to its reliance on familial evidence. In contrast, I have argued that a best interest test offers an important safeguard against a substituted judgement and offers the ability to make decisions concerning assisted dying from other perspectives such as relational dynamics. This chapter also included a discussion of how intending death should be an option in this analysis. From this, how to frame the role of the health care professional in providing assistance has also been established. This then led to a discussion concerning a right to assistance, arguing that this is underpinned by an instrumental goal of private positive relational interaction.

CONCLUSION

This thesis has identified the key care-based dimensions concerned with individuals who request assistance to end their life. In the first chapter, this thesis turned to an analysis of the current regulatory frameworks concerning assisted dying. In the second chapter a care-based ethic was established. This was illustrated by a description of the various care-based roles connected with the individual who requests assistance. From this position, a care-based ethic specifically pertinent to the individual who requests assistance was developed in both the second and third chapters. This highlighted the role of attempted statutory legislation, DPP guidance and contemporary medical law cases. Building on these previous chapters, in Chapter Four regulatory frameworks concerning four paradigmatic scenarios were reimagined from a care-based perspective established earlier in this thesis. Chapter One considered the current legal regulatory frameworks concerning assisted dying. This first chapter began with a discussion of the evaluation of the “eligibility criteria” contained in the attempted legislative Bills. In placing this at the start of Chapter One I was able to show that the assisted dying legislation and regulation should not be viewed as only applicable for those who have been diagnosed with a terminal illness, nor that the concept of suffering is inextricably linked to a medical diagnosis. This analysis included a brief example of individuals who live with dementia and a comparative assessment of legislation concerning assisted dying in the Netherlands and Belgium respectively. This gave me the opportunity to establish that the individual who requests assistance does not exist solely in a medical vacuum or in the last six-months of life. Rather the individual who requests assistance is premised on a subjective understanding of suffering.

Against this background I evaluated the role of the DPP’s guidelines and the decision on the death of Daniel James. This evaluation resulted in arguing that there had been *de facto* decriminalisation of a specific familial and compassionate assistance. In this chapter I raised the

associated implications connected with the use of family and compassion. I argued that compassion should not be connected to a disability and that the individual is no less compassionate because they agree that the individual should end their life. Instead, the use of compassion masked the DPP's reliance on an autonomous right to die. Further to this, in this chapter I argued that who can assist but avoid prosecution still remains ambiguous. With recourse to the decision on the death of Daniel James, I argued that the DPP should have given more consideration to the discussion of non-prosecution of the family friend.

Ultimately, it appears that the traditional familial paradigm and extended familial relationship could avoid prosecution. However, I argued that this relational definition remains ambiguous. This then led to a discussion of who should assist. With recourse to the principle approach established in Chapter One, I argued that health and social care professionals respectively should take on the role of assistance. This was argued for two primary reasons; firstly, where there is no familial assistance available the health and social care professional are the only appropriately trained actors who can assist. Secondly, and building on the first point raised, health and social care professionals (depending on what type of assistance is being provided) have the knowledge and experience to provide a safe and painless death. In addition, this chapter also discussed why it was important for the health and social care professional to discuss assisted dying with the individual who requires assistance; it reflects the reality of the individual who requests assistance and the associated end of life questions and options that arise in this context.

In Chapter Two, I provided a brief description of how a care-based ethic has developed and argued that a care ethic should be premised on a positive private relational interaction.

Building on this introductory context I discussed the role of autonomy in connection with the individual that requires assistance. I argued that a care-based approach can support individual decision-making. In the context of assisted dying I advocated the use of a procedural-based

approach to autonomy. I argue that the use of reflection is theoretically apt for end of life decision-making and reflects the values and preferences that are inextricably linked the decision-making process both for individuals with capacity and the comparison that can be made with the substituted judgment test as part of the MCA. From this basis I argued that a care-based understanding of the family should be premised on sentiment, emotion and material aid. By applying this definition, this chapter defined familial care-labour without a normative expectation of maternal and positive practices of care. This means that a plurality of caring practices and experiences can be incorporated into how we reconceptualise the role of assistance in a regulatory framework.

The role of the health care professional was also discussed in this chapter. I argued that the professional care role should be governed (predominantly) by Tronto's principled approach to care. It will be established that the health care professional should deploy the principles of attentiveness, responsibility and competency. In addition, this chapter has recalibrated the meaning of responsiveness as an active recognition of the patient who requests assistance. The discussion of professional care roles and its connection with societal engagement was underpinned by a communitarian approach to community responsibility for care. The final part of this chapter discussed the role of state agencies and their relationship with care. I argued that in order to achieve competent and successful care, care labour (both private and public) must be appropriately valued financially. This means that the state must facilitate care. With recourse to a discussion of the level of state facilitation of care this chapter concluded that the state must support a regulatory framework for assisted dying. This chapter has highlighted the importance of defining the care-based roles pertinent to each care actor without which care could be stripped of its societal and relational value and therefore the abilities to recognise the complexities and nuances which are inextricably linked to the plurality of caring relationships.

Having established a care ethic that is appropriate for the individual who requests assistance, in Chapter Three I discussed three contemporary medical law cases; *Aintree*, *Briggs* and *Nicklinson*. The two former cases were used to highlight the decision-making process concerning withdrawal of treatment. In support of Lady Hale's dicta in *Aintree* I argued that the determination of futility should be premised on a subjective understanding of the individual in question. In contrast, this chapter argued that when considering withdrawal intending death is a practiced and legitimate exercise. In addition, I argued that a substituted judgment is the most appropriate way to determine the interests of the individual that lacks capacity. This chapter then contrasted the judicial reasoning in *Nicklinson*. It is here where the legal inconsistencies between contemporary medical law cases (withdrawal of treatment and refusal treatment) were compared and resulted in a conclusion that there was an informal and implicit regulatory framework. An analysis of *Nicklinson* also included the argument that judicial reasoning failed to explicitly recognise any right to die arguments and the relational realities of assistance.

The final chapter concerned how a care-based approach can reconceptualise a regulatory framework for assisted dying. This was achieved by discussing the four paradigmatic circumstances that exemplify the individual who requests assistance. It was first demonstrated that a care-based understanding would not allow a regulatory response to a request for assistance from individuals who have both mental and physical capacity. This was then contrasted with the second scenario concerning individuals who lack physical capacity but have mental capacity. In this section I argued that a care-based approach to process-based autonomy supports a legal framework which supports autonomous decision-making in choosing to die. This chapter then discussed how decisions are made on behalf of those who lack both physical and mental capacity. This discussion focussed substantially on the best interest test. I argued that the best interest test should be utilised but be inclusive of a

substituted judgment. However the substituted judgment should be broadened in scope to include a representative view of how the practice of care can influence both formal and informal structures that determine the views of others. Building on this, this thesis then contrasted the conceptual differences between passive and active euthanasia in response to individuals living with dementia. The final part of this chapter then focussed on the importance of the knowledge and expertise of the health care professional and suggested that they should be included as active members in a new regulatory model for assisted dying. This chapter then ended with a discussion of the right to assistance from a care-based perspective of relational interaction.

This thesis has illustrated the inextricable link between death, dying and care. If assisted dying is to be appropriately regulated such a framework must reflect the realities of care both in the private and public domain and the influence this has on legislative safeguards, professional care providers and state provision of care respectively. By legislating from a care-based perspective, a deeper response which is reflective of the complexities of this scenario can be achieved. Although this may mean a more complex and problematic regulatory process I argue that this is the best mechanism to ensure we legislate in favour of assisted dying successfully. Care incorporates all parts of our life and yet it is disregarded when we discuss death, dying and assisted dying. If we are to appropriately reconceptualise a regulatory framework for the individual who requests assistance we must engage with the realities of care. By doing this we can establish a better experience for those connected to requests for assistance to end life who both provide and receive such care.

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