Physician-assisted death in England and Wales

A thesis submitted for the degree of Doctor of Philosophy in Law

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Abstract

The thesis examines if the recent legal developments on assisted death in England and Wales have addressed the needs of society and the concerns of those seeking an assisted death. Despite assisted suicide being a crime in England and Wales, many British citizens successfully obtain an assisted suicide by travelling abroad. With the help of loved ones, they patronise right-to-die organisations in jurisdictions with more permissive laws on suicide. Meanwhile, the prosecution of those who assist a suicide is subject to an uncertain discretion of the DPP, whose prosecuting policy effectively decriminalises ‘compassionate assisted suicides’. Inconsistencies in the law on assisted death between the legal prohibition of assisted suicide, and legally permitted end-of-life medical decisions will also be examined. Whilst assisted death is a crime, physicians are legally permitted to withhold or withdraw life-sustaining treatment from patients. The extent to which a patient’s ‘quality of life’ has been a factor in these inconsistent decisions will be analysed. The thesis will show that the present prohibition against assisted suicide in England and Wales is legally and morally indefensible. Whilst investigating whether assisted suicide should be legalised in England and Wales, the thesis undertakes a comparative analysis of six jurisdictions from around the world. It also evaluates the ‘slippery slope’ argument, i.e. whether a law permitting assisted death for a restricted group of people would inevitably lead to assisted death being practised beyond that group. The thesis will conclude that there is a strong case for providing the legal option of physician-assisted suicide to patients experiencing a poor and unacceptable quality of life due to unbearable pain and suffering brought about by terminal illness.

Dedication

To my parents and husband

I thank my parents Stephen and Ann for being a constant source of
encouragement and motivation.
Your belief in me has sustained me through many difficult moments.
I persevere because of your life-long sacrifices, and your enduring love and devotion.
My love to you both.

I thank my dearest husband Michael who has supported and comforted me
through some of the 'darker' periods of this thesis.
You continuously amaze me with your unfailing love, and unfaltering commitment to me.
For your patience, and understanding, I will always be indebted.
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Melanie Selvalingam

List of Abbreviations

5P	:	II. Zivilabteilung - Staatsrecht [Second Civil Division - State law] (Supreme Court list, Switz)
AD Bill 2013	:	Assisted Dying HL Bill (2013-14) 24
ADMD	:	Association pour le Droit de Mourir dans la Dignité [Association for the Right to Die with Dignity] (Switz)
ADTI Bill 2004	:	Assisted Dying for the Terminally Ill HL Bill (2003-04) 17
ADTI Bill 2005	:	Assisted Dying for the Terminally Ill HL Bill (2005-06) 36
AGVE	:	Aargauischen Gerichts- und Verwaltungsentscheide [Aargau Court and Administrative Decisions] (case report series, Switz)
AHA	:	Area Health Authority
AJP	:	Aktuelle Juristische Praxis [Current Legal Practice] (law journal and case report series, Switz)
ALSAQ-40	:	Amyotrophic Lateral Sclerosis Assessment Questionnaire (medical instrument to measure quality of life)
ANH	:	Artificial Nutrition and Hydration (medical treatment)
APPG	:	All Party Parliamentary Group
art/arts	:	article/articles
Aust	:	Australia
BÄK	:	Bundesärztekammer [German Medical Association]
BBC	:	British Broadcasting Corporation
BE	:	Beschwerdeverfahren (Zivilsachen) [Complaints procedure (civil matters)] (Switz)
Belg	:	Belgium
Belgian Act	:	Belgian Act Concerning Euthanasia 2002
BGBl	:	Bundesgesetzblatt [Federal Law Gazette] (Ger)
BGH	:	Bundesgerichtshof [Federal Court of Justice] (Ger)
BMA	:	British Medical Association
BMJ	:	British Medical Journal
BOP	:	Belgian Order of Physicians
BPC	:	Belgian Penal Code
BSA	:	British Social Attitudes (annual survey by the National Centre for Social Research)
CCP	:	Code for Crown Prosecutors
CFCE	:	Commission Féderale de Contrôle et d'évaluation de l'euthanasie [Federal Control and Evaluation Commission] (Belg)
ch/chs	:	chapter/chapters
Cir	:	Circuit (US)
CMD	:	Code of Medical Deontology (Belg)
CNK	:	Care Not Killing (an organisation which campaigns against the legalisation of assisted death)
CPR	:	CardioPulmonary Resuscitation (medical treatment)
CPS	:	Crown Prosecution Service
CQC	:	Care Quality Commission

CUP	:	Cambridge University Press
DDA	:	Death with Dignity Act (Oregon)
DGHS	:	Deutsche Gesellschaft für Humanes Sterben [German Society for Humane Death]
DGP	:	Deutsche Gesellschaft für Palliativmedizin [German Association for Palliative Medicine]
DPA	:	Dutch Paediatric Association
DPC	:	Dutch Penal Code
DPP	:	Director of Public Prosecutions
DPP’s Policy	:	Policy for Prosecutors in Respect of Cases of Encouraging or Assisting Suicide: Issued by the Director of Public Prosecutions (CPS, February 2010)
Dutch Act	:	Termination of Life on Request and Assisted Suicide (Review Procedures) Act 2001 (Neth)
E	:	Entscheidungen [Judgment] (Ger)
e.V.	:	eingetragener Verein [registered association] (Ger)
ECHR	:	European Convention on Human Rights
ECtHR	:	European Court of Human Rights
ed/eds	:	editor/editors
edn	:	edition
EDS	:	Exit Deutsche Schweiz [Exit German Switzerland] (a ‘right-to-die’ organisation)
EOL	:	End of Life
EORTC	:	European Organization for Research and Treatment of Cancer
FACIT-Pal	:	Functional Assessment of Chronic Illness Therapy – Palliative Care (medical instrument to measure quality of life)
fn/fnn	:	footnote/footnotes
GCC	:	German Criminal Code
Ger	:	Germany
GMC	:	General Medical Council
GP	:	General Practitioner
HPAD	:	Healthcare Professionals for Assisted Dying (organisation which campaigns in favour of the legalisation of assisted death)
HQLI	:	Hospice Quality of Life Index (medical instrument to measure quality of life)
Interim Policy	:	Interim policy for Prosecutors in Respect of Cases of Assisted Suicide (CPS, September 2009)
ITV	:	Independent Television
KNMG	:	Koninklijke Nederlandse Maatschappij tot bevordering der Geneeskunst [Royal Dutch Medical Association] (Neth)
KNMP	:	Koninklijke Nederlandse Maatschappij ter bevordering der Pharmacie [Royal Dutch Society for the Advancement of Pharmacy] (Neth)
LCP	:	Liverpool Care Pathway for the Dying Patient
LEIF	:	LevensEinde InformatieForum [Life End Information Forum] (Belg)
LPA	:	Lasting Power of Attorney
MB	:	Moniteur Belge (the government gazette of Belgium)
MBPSL	:	Medical Behaviour that Potentially Shortens Life
MCA	:	Mental Capacity Act 2005
MDB	:	Medical Disciplinary Board (Belg)
MQLS	:	McMaster Quality of Life Scale (medical instrument to measure quality of life)

MQOL	McGill Quality of Life questionnaire (medical instrument to measure quality of life)
MVQOLI	Missoula-VITAS Quality of Life Index (medical instrument to measure quality of life)
n/nn	footnote/footnotes
NCPC	National Council for Palliative Care
NDYUK	Not Dead Yet United Kingdom (organisation which campaigns against the legalisation of assisted death)
Neth	the Netherlands
NHS	National Health Service
nr	nummer [number] (Neth)
NT	Northern Territory, Australia
NTP	Northern Territory Parliament
ODHS	Oregon Department of Human Services
OPHD	Oregon Public Health Division
Or	Oregon
Or Rev Stat	Oregon Revised Statutes
OSHD	Oregon State Health Division
OUP	Oxford University Press
PAD Bill 2003	Patient (Assisted Dying) HL Bill (2002-03) 37
PANICOA	Prevention of Abuse and Neglect in the Institutional Care of Older Adults (a research initiative of King's College London and the National Centre for Social Research)
para/paras	paragraph/paragraphs
PCA	Palliative Care Act (Belg)
PCTMC	Principles Concerning Terminal Medical Care (of the BÄK, Ger)
PVS	Permanent Vegetative State (medical condition)
Que	Quebec, Canada
r/rr	rule/rules
RCP	Royal College of Physicians
RCS	Royal College of Surgeons
ROTI Act	Rights if the Terminally Ill Act 1995 (NT)
ROTI Amendment Act	Rights if the Terminally Ill Amendment Act 1996 (NT)
RRC	Regional Review Committee (Neth)
s/ss	section/sections
SA 1961	Suicide Act 1961 (England & Wales)
SAMS	Swiss Academy for Medical Sciences
SCEN	Steun en Consultatie bij Euthanasie in Nederland [Support and Consultation on Euthanasia in the Netherlands]
SEIQoL	Schedule for the Evaluation of Individual Quality of Life (medical instrument to measure quality of life)
SPC	Swiss Penal Code
Stb	Staatsblad [Statute Book] (Neth)
StR	Revisionen in Strafsachen [Appeals on Questions of Law in Criminal Cases] (Ger)
sub-s/sub-ss	sub-section/sub-sections

Switz	:	Switzerland
TGR	:	Tijdschrift voor Gezondheidsrecht [Journal of Health Law] (Neth)
tr/trs	:	translator/translators
UK	:	United Kingdom
US	:	United States of America
VB	:	Vorsorgliche Beweisabnahme [Pre-trial taking of Evidence] (Switz)
vol/vols	:	volume/volumes
WL	:	Westlaw
ZB	:	Zivilsachen Beschwerden [complaints in Civil Matters] (Ger)
ZBl	:	Zentralblatt für Staats- und Verwaltungsrecht [Central Journal of Constitutional and Administrative Law] (Switz)

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Australia

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Belgium

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Loi relative aux soins palliatifs F 2002-3849 [S C 2002/22868] du 14 Juin 2002 [Act Concerning Palliative Care] MB 26 October 2002, 49160

Germany

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An NHS Trust v L [2013] EWHC 4313

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B (Adult: Refusal of Medical Treatment), Re [2002] EWHC 429 (Fam), [2002] 2 All ER 449, 65 BMLR 149

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Switzerland

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Chapter 1: Overview, Purpose and Research Methodology

1.1 Introduction

The thesis examines the law on assisted death in England and Wales. Assisted death has recently been the subject of much debate in England and Wales, in response to which this thesis proposes law reform. Within this thesis, ‘assisted death’ collectively refers to both assisted suicide and euthanasia. Assisted suicide refers to the act of assisting another to commit suicide at their request. The person requesting assistance performs the act causing death. Euthanasia, on the other hand, refers to the termination by one person of another person’s life to put an end to pain and suffering (sometimes referred to as ‘mercy killing’). Both assisted suicide and euthanasia are unlawful in England and Wales. Assisted suicide is prohibited by section 2(1) of the Suicide Act 1961 (‘SA 1961’).[1] As euthanasia is not specifically addressed by the law, it is prohibited through application of the law of murder. Although the main focus of this thesis is on assisted suicide, it addresses related issues on euthanasia.

Calls for assisted death in England and Wales to be legalised have recently been brought into sharp focus for three main reasons. First, whilst assisted suicide is a crime if committed in England and Wales, it remains open to those British citizens who are able to travel abroad and seek assistance at ‘right-to-die’ organisations, such as Dignitas in Switzerland.[2] Secondly, section 2(4) of the SA 1961 provides that no prosecution shall be instituted for the offence of assisted suicide except with the consent of the Director of Public Prosecutions (‘DPP’).[3] This requirement of a ‘consent to prosecute’ from the DPP suggests that at least some instances of assisted suicide are not regarded as culpable. Thirdly, wide publicity given to the case of Tony Nicklinson has commanded extensive public attention.

The case of Tony Nicklinson is briefly discussed below. It is the most recent ‘right-to-die’ case to highlight the plight of British citizens who competently decide that

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[1] The Suicide Act 1961 sub-s 2(1) (as amended in 2009) provides that a person commits an offence if they do an act ‘capable of encouraging or assisting the suicide or attempted suicide of another person’, and that act ‘was intended to encourage or assist suicide or an attempt at suicide’.

[2] See section 1.2.1 for ‘suicide tourism’.

[3] See section 1.2.2 for ‘the DPP’s consent’.

they do not wish to continue living, and who thus seek an assisted death in England and Wales.

1.1.1 *The case of Tony Nicklinson*

Tony Nicklinson's 'right-to-die' case went further than previous high profile 'right-to-die' cases that centered around assisted suicide.[4] Nicklinson had suffered a stroke which left him with a condition known as 'locked-in' syndrome. As he was almost completely paralysed from the neck down, he was incapable of taking his own life even with assistance. Nicklinson was dependent on others to end his life for him through an act of euthanasia. He was capable of travelling to Dignitas with his wife's help. However, euthanasia is illegal in Switzerland, and thus not performed at Dignitas. Nicklinson's desire to end his life accordingly led him to challenge the current law in England and Wales on assisted suicide and euthanasia. He argued that it was illogical, harsh and hypocritical for the law to prohibit such practices when it does not prohibit suicide and allows patients to refuse life-sustaining treatment.[5] In 2012, Nicklinson requested that the law on homicide be changed so that a physician could lawfully administer him with a lethal injection and yet remain immune from prosecution on the grounds of 'necessity'. He sought a declaration that the common law defence of necessity[6] should be made available against both a charge of murder in the case of voluntary euthanasia,[7] and against a charge of assisted suicide under section 2(1) of the SA 1961.[8]

Nicklinson was unsuccessful in his application. Lord Justice Toulson held that:

> A decision by the court to alter the common law so as to create a defence to murder in the case of active voluntary euthanasia would be to introduce a major change in an area where there are strongly held conflicting views,

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[4] The cases of Diane Pretty, Debbie Purdy and Daniel James, discussed in ch 2.

[5] A Garwood-Gowers, 'A Right to Die? The Tony Nicklinson case' *The Times* (London, 28 June 2012). See ch 2 for the legality of the refusal of life-sustaining treatment.

[6] See *Re A (Children) (Conjoined Twins: Surgical Separation)* [2000] 4 All ER 961, discussed in ch 2.

[7] 'Voluntary euthanasia' is where euthanasia is performed on an individual, upon the individual's expressed wishes.

[8] Nicklinson also sought a declaration that the current law of murder and/or of assisted suicide is incompatible with his right to respect for private life under Article 8 of the European Convention on Human Rights, in so far as it criminalises voluntary euthanasia and/or assisted suicide. This issue was rejected by the court, as it had been dealt with in great detail by the House of Lords in *Purdy*. *R (Nicklinson) v Ministry of Justice* [2012] EWHC 2381 [18],[148].

> where Parliament has rejected attempts to introduce such a change, and where the result would be to create uncertainty rather than certainty…it is hard to imagine that Parliament would legalise any form of euthanasia without a surrounding framework regarding end of life care and without procedural safeguards…It is not for the court to decide whether the law about assisted dying should be changed and, if so, what safeguards should be put in place. Under our system of government these are matters for Parliament to decide, representing society as a whole, after Parliamentary scrutiny, and not for the court on the facts of an individual case or cases.[9]

In a concurring judgment, Mr Justice Royce held:

> Some will say the Judges must step in to change the law.…But the short answer is that to do so here would be to usurp the function of Parliament…Any change would need the most carefully structured safeguards which only Parliament can deliver…These are matters which must be adjudicated upon by Parliament and not Judges or the DPP as unelected officers of state.[10]

Nicklinson refused food and medical treatment after failing in his application to the High Court. He died of pneumonia a week after the High Court ruling.[11]

The judges in Tony Nicklinson's case echoed Lord Goff's earlier judgment from 1994 in Bland's case:

> Euthanasia is not lawful at common law. It is of course well known that there are many responsible members of our society who believe that euthanasia should be made lawful; but that result could, I believe, only be achieved by legislation which expresses the democratic will that so fundamental a change should be made in our law, and can, if enacted,

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[9] ibid [84],[85],and[150].

[10] ibid [151]. This is merely an outline of the judicial review of Nicklinson's case in the High Court. As will be discussed in ch 2, Nicklinson's wife's appeal to the Court of Appeal was dismissed. See Court of Appeal judgment in Nicklinson, Lamb and Martin's joint appeal: *R (Nicklinson) v Ministry of Justice* [2013] EWCA 961.

[11] S Boseley, 'Tony Nicklinson dies after losing "right to die" legal battle' *The Guardian* (London,22 August 2012).

> ensure that such legalised killing can only be carried out subject to appropriate supervision and control.[12]

As the main focus of this thesis is on assisted suicide, it will not resolve cases like Tony Nicklinson's.[13] It will, however, address issues similar to those which pertain to euthanasia. There have recently been several campaigns in England and Wales for a change in the law on assisted death, all of which have fuelled debate on whether competent individuals should be lawfully assisted to die. The following section will explain the problem that this thesis aims to address by highlighting three principal sources of controversy in this debate.

1.2 The problem to be addressed

1.2.1 *The first source of controversy: suicide tourism*

The first source of controversy in the debate on the legalisation of assisted death is that while assisted suicide is a crime in England and Wales, there frequently occurs what has been euphemistically referred to as 'suicide tourism'.[14] Today, many British citizens wanting to end their lives are taking advantage of the relatively liberal suicide laws of Switzerland. Assisted suicide is not only lawful in Switzerland, but is also available to non-Swiss nationals.[15] The Swiss 'right-to-die' organisation Dignitas, which assists people to commit suicide, is currently the most popular destination for these so-called 'suicide tourists'.[16] As at February 2013, figures published by Dignitas[17] showed that

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[12] *Airedale NHS Trust v Bland* [1993] AC 789 (Bland's case), at 865, discussed in detail in chs 2 and 4.

[13] In cases such as Nicklinson's, patients have been known to resort to refusing food and fluids, thus dying of starvation or dehydration or other complications in order to achieve death. See G Saunders, 'Letters: My partner Meg Taylor's unassisted dying' *The Guardian* (London,17 July 2013).

[14] B Falconer, 'Death Becomes Him' *Atlantic Monthly* (Washington, March 2010) 68, 70.

[15] MA Branthwaite, 'Should patients be able to choose physician-assisted suicide at the end of their lives?' (2006)7 Lancet Oncology 602.

[16] See statistics of assisted suicide deaths at Dignitas at 'Accompanied suicide of members of Dignitas, by year and by country of residency 1998-2012' (Dignitas,2013) <www.dignitas.ch/images/stories/pdf/statistik-ftb-jahr-wohnsitz-1998-2012.pdf> accessed 31 July 2013.

[17] 'Statistics' page of Dignitas website <www.dignitas.ch/index.php?option=com_content&view=article&id=32&Itemid=72&lang=en> accessed 4 February 2013.

approximately 215 British citizens had been helped to end their lives since 1998.[18] The figures also showed that Dignitas had 821 members from Britain at the end of 2012.[19]

British subjects who have ended their lives at Dignitas have had a wide range of medical conditions. Cases range from the terminally ill with cancer or motor neurone disease, to those with non-fatal conditions like progressive multiple sclerosis and spinal cord injuries. As observed by Seale in 2010, 'one in five [requesting assisted suicide in Dignitas] has no fatal condition but rather, for example, arthritis, osteoporosis, 'general weakness', blindness, or mental disorders, usually depression'.[20] In September 2008, 23-year-old Daniel James, who had sustained a serious spinal injury in a rugby accident and become paralysed, became the youngest Briton to receive assistance to die at Dignitas.[21] In March 2011, an 84-year-old arthritic British woman committed suicide at Dignitas simply because she did not want to die of old age.[22] She left a note saying she wished to escape the 'long period of decline, sometimes called "prolonged dwindling", that so many people unfortunately experience before they die'.[23] A more recent case in May 2013 involved an 83-year-old British man who did not want to face the agony of progressive dementia. Realising the strain that his incurable dementia would almost certainly place on his family, he did not want to become a burden to them. He is understood to be the first Briton to have used the services at Dignitas solely due to dementia.[24]

Patients travelling to Dignitas are often either accompanied by their loved ones, or have travel arrangements made by loved ones on their behalf.[25] Several such incidents of loved ones assisting patients to travel to Dignitas have been investigated by police as there remains a question of whether such acts constitute suicide 'assistance'. However,

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[18] 'Accompanied suicide of members of Dignitas, by year and by country of residency 1998-2012' (n17).

[19] 'Members of Dignitas by country of residency as of 31 December 2012' (Dignitas,2013) <www.dignitas.ch/images/stories/pdf/statistik-mitglieder-wohnsitzstaat-31122012.pdf> accessed 4 February 2013. These are the annually published February statistics for 2013.

[20] C Seale, 'Do it properly or not at all' (2010)340 BMJ c1719.

[21] R Edwards, 'Parents of rugby player in Dignitas assisted suicide will not face charges' *The Telegraph* (London, 9 December 2008).

[22] M Hanson, 'Living in fear of the "prolonged dwindle"' *The Guardian* (London,4 April 2011).

[23] J Adetunji, 'Assisted dying campaigners split over right to die for those not terminally ill' *The Guardian* (London,3 April 2011).

[24] M Hall, 'Pensioner has become first British dementia sufferer to die at suicide clinic' *The Telegraph* (London,30 May 2013).

[25] K Starmer, Crown Prosecution Service, 'Decision on Prosecution — The Death by Suicide of Daniel James' (9 December 2008) paras 1, 4 <www.cps.gov.uk/news/articles/death_by_suicide_of_daniel_james> accessed 19 June 2014.

to date, none of the relatives and friends involved have been prosecuted for assisted suicide.[26] Three cases in particular — Diane Pretty, Daniel James, and Debbie Purdy — exemplify the complexity of prosecuting suicide tourism.[27] These will be discussed in Chapter Two.

1.2.2 *The second source of controversy: the DPP's consent*

The second source of controversy in the debate on the legalisation of assisted death is caused by uncertainty over how the DPP gives her consent to initiate a criminal prosecution for assisted suicide.[28] Due to a lack of prosecutions relating to suicide tourism, Debbie Purdy,[29] a multiple sclerosis sufferer, sought clarification from the British courts as to whether her husband would be prosecuted if he assisted her to travel to Dignitas. On appeal to the House of Lords, she requested advice on the circumstances in which a person would likely be prosecuted for helping another to travel abroad to commit suicide.[30] In July 2009, the House of Lords ruled that the law was not sufficiently clear in this area. The House of Lords instructed the DPP to produce an offence-specific policy, explaining how decisions are taken in assisted suicide cases, for the benefit of Purdy and others like her who are contemplating ending their lives at 'right-to-die' organisations abroad.[31] Lord Hope distinguished assisted suicide cases that would ordinarily invite prosecution, from 'uncertain' cases involving the 'compassionate assistance' of those who are terminally ill or incurably disabled, who competently decide to end their lives at 'right-to-die' organisations abroad and require assistance to do so. As His Lordship's judgment in *Purdy* states:

> [A person] may be prosecuted if there is enough evidence to sustain a prosecution and it is in the public interest that this step should be taken. But the practice that will be followed in cases where [there is] compassionate assistance…is far less certain.[32]

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[26] See 'Latest Assisted Suicide Figures' (CPS, 1 March 2014) <www.cps.gov.uk/publications/prosecution/assisted_suicide.html> accessed 2 May 2014.

[27] 'Assisted suicide: Diane Pretty, Debbie Purdy and Daniel James' *The Telegraph* (London,23 September 2009).

[28] Suicide Act 1961 sub-s.2(4).

[29] Debbie Purdy was also a right-to-die campaigner for Dignity in Dying, a British pro-assisted death lobby group.

[30] DM Cohen, 'Comment: Looking For A Way Out: How to Escape The Assisted Suicide Law In England' (2010)24 Emory Int'l L.Rev. 697.

[31] *R (Purdy) v DPP* [2009] UKHL 45[56].

[32] ibid [27].

His Lordship goes on to further state that:

> The [Code for Crown Prosecutors] will normally provide sufficient guidance…In most cases its application will ensure predictability and consistency…But that cannot be said of cases where the offence in contemplation is aiding or abetting the suicide of a person who is terminally ill or severely and incurably disabled, who wishes to be helped to travel to a country where assisted suicide is lawful and who, having the capacity to take such a decision, does so freely and with a full understanding of the consequences.[33]

Following from the House of Lords' decision in *Purdy*, the DPP published the prosecuting policy on assisted suicide ('DPP's Policy') on 25 February 2010.[34] The DPP's Policy sets out the public interest factors that are for and against a prosecution for assisted suicide. The policy distinguishes compassionate assistance provided to someone who reaches a voluntary and settled decision to commit suicide, from malicious, irresponsible and professionally organised help.

The thesis will show that the DPP's Policy does not meet the needs of society in England and Wales. The DPP's Policy has effectively decriminalised 'compassionate' assisted suicides in England and Wales, by making the motive of the person assisting a crucial factor. As observed by Dignity in Dying (a British lobby group campaigning for the legalisation of assisted death),[35] whilst the DPP's Policy effectively permits 'compassionate' assisted suicides, such 'compassionate assistance' still remains illegal under the SA 1961. Further, by deterring healthcare professionals[36] from providing suicide assistance,[37] the DPP's Policy encourages those requiring suicide assistance to rely on 'amateur assistance' from non-medically qualified people such as friends and

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[33] *Purdy* (HL)(n31)[54]. The Code for Crown Prosecutors gives guidance to prosecutors on the general principles to be applied when making decisions about prosecutions: Crown Prosecution Service (CPS), *The Code for Crown Prosecutors* (2013)('CCP'). See paras1.13 and 4.12 of the CCP.

[34] CPS, *Policy for Prosecutors in Respect of Cases of Encouraging or Assisting Suicide: Issued by the Director of Public Prosecutions* ('DPP's Policy')(February 2010).

[35] See Campaign for Dignity in Dying <www.dignityindying.org.uk> accessed 17 May 2013.

[36] The Court of Appeal in Nicklinson's case addressed the issue of the participation of healthcare professionals in assisted suicides. The issue was raised by an individual called 'Martin' whose case was part of a joint appeal with Nicklinson's wife and another, Lamb. The Court of Appeal requested the DPP to amend his policy to provide more clarity for healthcare professionals. See Court of Appeal judgment in Nicklinson, Lamb and Martin's joint appeal: *Nicklinson* (CA)(n10). This is discussed in detail in ch2.

[37] DPP's Policy (n34) para43(14).

family members. As well as the risk of 'botched' or failed suicides, this leaves family and friends with difficult choices — whether to unlawfully assist a loved one who is desperate to end their suffering, or whether to deny them the death that they want.[38] The DPP's Policy is discussed in detail in Chapter Two.

1.2.3 *The third source of controversy: inconsistencies in the law*

The third source of controversy in the debate on the legalisation of assisted death is that there is tension due to inconsistencies in the current law of England and Wales between the legal prohibition of assisted death and other end-of-life medical decisions which are legally permitted. These inconsistencies will be addressed in detail in section 2.3.

As discussed in Chapter Two, in cases where physicians have withheld or withdrawn life-sustaining treatment from incompetent patients, the English courts have justified such medical decisions by applying the 'acts and omissions' distinction. The inconsistency in English law between the prohibition on assisted death and the lawfulness of the withdrawal of life-sustaining treatment from incompetent patients was acknowledged by the House of Lords in Bland's case. As Lord Mustill in Bland's case held:

> The…distinction drawn by the criminal law between acts and omissions…carries with it…a distinction between…'mercy killing' where active steps are taken in a medical context to terminate the life of a suffering patient, and a situation…where the…conduct has the aim…of terminating the life…by withholding…the basic necessities of life. [Nevertheless], however much the terminologies may differ the ethical status of the two courses of action is for all relevant purposes indistinguishable.[39]

Lord Goff similarly held, 'It is true that the drawing of this ["acts and omissions"] distinction may lead to a charge of hypocrisy.'[40]

Medical decisions with a 'double effect', in which physicians may lawfully administer palliative medication which has a possible life-shortening effect, also demonstrate an

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[38] See 'Kay Gilderdale: A Devoted Mother' *The Guardian* (London,25 January 2010).

[39] Bland's case (n12) 887 and 891.

[40] ibid 865.

inconsistency in the current English law. The tension in the law here is that, whilst a physician is legally prohibited from administering or supplying a lethal medication to a patient at their request, a physician is legally permitted to administer a patient (with or without their consent) with lethal amounts of palliative medication, with the intention of alleviating pain and suffering, even if it is foreseen that the patient's death will be hastened as a result.

A third inconsistency in the law relates to a competent patient's legal right to refuse life-sustaining treatment, even though the same patient is not legally permitted to make a voluntary and informed request for an assisted death. This inconsistency in the law was brought to light in 2002, by the cases of *Pretty*[41] and *Re B*[42]. Both cases involved competent women with debilitating illnesses which had left them paralysed from the neck down. In *Pretty*, Mrs Pretty who was terminally ill was denied a court order permitting her husband to assist her to travel abroad to Dignitas for an assisted suicide. By contrast, in *Re B*, Ms B who was not terminally ill was allowed by the court to refuse a life-sustaining ventilator which kept her alive.

The thesis adopts the view that these end-of-life medical decisions which are legally permitted, are morally indistinguishable from assisted death as they equally hasten death.[43] The above-mentioned inconsistencies in the law, and the legal and ethical distinctions between the law prohibiting assisted death and legally permitted end-of-life medical decisions will be considered in Chapters Two and Three. The thesis considers that the current English law on assisted death is less than satisfactory and is in need of Parliamentary reform.

The following section sets out the aims and objectives of the thesis. It describes the main areas of concern which are shaping the debate on assisted death in England and Wales, and which are driving the calls for possible law reform. It also outlines what the thesis aims to achieve in terms of analysis, arguments, and proposed reforms.

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[41] *R (Pretty) v DPP* [2001] UKHL 61.

[42] *Re B (Adult: Refusal of Medical Treatment)* [2002] 2 All ER 449,see ch2.

[43] T Tannsjo, 'Moral dimensions' (2005)331 BMJ 689.

1.3 Aims and objectives

Studies in the UK have found that the reasons the terminally ill want an assisted death include pain and anticipated pain, fear of indignity, loss of control and cognitive impairment, and not wanting to be a burden.[44] Similarly, a study in 2010 by Price et al found that the reasons for a desire for assisted death among terminally ill patients are, i) social factors that included financial difficulties and lower levels of social support, ii) illness-related factors that included having a symptom burden that had a greater effect on the individual's identity or emotions, and a lower sense of personal control and control over treatment, and iii) a loss of dignity.[45] There are many terminally ill patients in England and Wales who suffer a protracted dying process.[46] Some with debilitating conditions choose to end their lives at a relatively early stage in their illness, whilst they are still physically able to do so, resulting in them dying prematurely.[47] This thesis aims to address these concerns. It will be argued that there is a strong case for allowing competent patients who are terminally ill to make an autonomous request for physician-assisted suicide if they are experiencing a poor and unacceptable quality of life due to unbearable pain and suffering brought about by a terminal illness.

The thesis will examine the developments in English law that have had an impact on the law of assisted death to demonstrate that they have not met the needs of society, especially the concerns of those seeking an assisted death in England and Wales. This thesis will also examine legally permitted end-of-life medical decisions in England and Wales. It will demonstrate that due to the inconsistencies noted above in section 1.2.3, the current prohibition on assisted death is legally and morally indefensible. It will be argued that a law which permits physician-assisted suicide in particular circumstances is desirable to regulate end-of-life decisions.

The social and ethical influences affecting the development of the law on assisted death in England and Wales will be considered in this thesis. These influences include a rise in individualism, an ageing population, the sanctity of life, a right to self-determination, medical paternalism, and personal autonomy. The impact of these influences on both

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[44] A Chapple et al, 'What people close to death say about euthanasia and assisted suicide: a qualitative study' (2006)32 Journal of Medical Ethics 706,706.

[45] A Price et al, 'Prevalence, course and associations of desire for hastened death in a UK palliative population: a cross-sectional study' (2011)1(2) BMJ Supportive&Palliative Care 140.

[46] *Pretty* (HL)(n41).

[47] P Allbeck et al, 'Increased suicide rate in cancer patients' (1989)42 J Clin Epidemiol 611.

the law of assisted death, and the laws which govern end-of-life medical decisions will be examined. In regard to personal autonomy and self-determination, it will be argued that a law which permits physician-assisted suicide in particular circumstances will ensure that competent patients who are terminally ill are given a level of respect which is comparable to those who already influence the manner and timing of their death by refusing life sustaining treatment.

There have been repeated calls for law reform in England and Wales. Over the past 10 years, there have also been several draft Bills proposed to legalise assisted death for the terminally ill. These include Lord Joffe's Assisted Dying for the Terminally Ill Bill 2004 ('ADTI Bill 2004').[48] The House of Lords set up a Select Committee ('2004 Select Committee') to examine the legal and ethical issues of this Bill on assisted dying, and to make recommendations for any future Bill.[49] For reasons discussed in Chapter Two, the Bill was not tabled for a second time. In September 2010, Lord Falconer's Commission on Assisted Dying ('the Commission') evaluated the present law and explored a possible framework for assisted dying that might be acceptable to the general public.[50] The Commission's 2012 Report found that 'the current legal status of assisted dying is inadequate and incoherent' and that there is 'a strong case for providing the choice of assisted dying for terminally ill people'.[51] Based on the recommendations of the Commission's 2012 Report, an All-Party Parliamentary Group on Choice at the End of Life[52] together with Dignity in Dying[53] drafted a Bill to amend the law.[54] The draft Bill provided for competent terminally ill adults to have the option of an assisted death, subject to strict upfront safeguards.[55] After a period of public consultation from July to

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[48] Assisted Dying for the Terminally Ill HL Bill (2003-04) 17 ('ADTI Bill 2004').

[49] Select Committee on the Assisted Dying for the Terminally Ill Bill, *Assisted Dying for the Terminally Ill Bill [HL] Vol I* (2004-05,HL86-1) para269.

[50] The Commission on Assisted Dying was not a governmental or parliamentary commission. See more details on the Commission at 'About the Commission on Assisted Dying' (*Commission on Assisted Dying*,2010) <www.commissiononassisteddying.co.uk/about-the-commission-for-assisted-dying> accessed 2 August 2013.

[51] *Report of the Commission on Assisted Dying* (Demos,2012) 285.

[52] The APPG on Choice at the End of Life believes that provided sufficient legal safeguards are in place, mentally competent terminally ill adults should have the right to an assisted death. See APPG on Choice at the End of Life and Dignity in Dying, *Safeguarding Choice – A draft Assisted Dying Bill for consultation* <www.appg-endoflifechoice.org.uk/pdf/appg-safeguarding-choice.pdf> accessed 23 July 2013.

[53] Dignity in Dying supports the aims of the APPG on Choice at the End of Life and provides the secretariat to the Group. Refer to n35.

[54] See All Party Parliamentary Group (APPG) on Choice at the End of Life and Dignity in Dying, 'Frequently Asked Questions' <www.appg-endoflifechoice.org.uk/frequently_asked_questions> accessed 23 July 2013.

[55] APPG, *Safeguarding Choice – A draft Assisted Dying Bill for consultation* (n52).

November 2012,[56] Lord Falconer redrafted this Bill, and introduced it as the Assisted Dying Bill 2013 ('AD Bill 2013') on 15 May 2013.[57] To inform the current law reform agenda in England and Wales, the thesis will evaluate the ADTI Bill 2004, the recommendations of the 2004 Select Committee,[58] the Commission's 2012 Report, and the AD Bill 2013.

The thesis adopts the view that the current English law is out of step with public opinion. Recent opinion polls conducted in the UK consistently demonstrate a high level of public support for assisted death for the terminally ill.[59] The 2005[60] and 2007[61] *British Social Attitudes* ('*BSA*') surveys show that 80% of respondents thought that assisted dying should be allowed for terminally ill patients. A July 2009 Populus poll for *The Times* newspaper similarly found that 74% of respondents supported physician-assisted suicide in particular circumstances, of which 95% thought that it should be legal for people who are terminally ill.[62] These opinion polls are relevant as they indicate a perception by the public that their needs are not being met by the current law on assisted death in England and Wales.

The British public are also generally in favour of a law that allows physicians to assist the suicides of their patients i.e. physician-assisted suicide. This is demonstrated by Chappel et al's 2006 study on assisted death which found that those contemplating suicide wanted to end their lives with medical help and in the company of family or friends.[63] It will be argued that by allowing physicians to assist in suicides, this would address the issue of medical complications which may arise during a suicide and lower the risk of 'botched' or failed suicides.

The thesis will argue that a law permitting physician-assisted suicide that restricts eligibility to people with terminal illness would be in line with the current public

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[56] APPG on Choice at the End of Life and Dignity in Dying, 'Bill consultation: Latest news' <www.appg-endoflifechoice.org.uk/bill_consultation> accessed 23 July 2013.

[57] Assisted Dying HL Bill (2013-14) 24 ('AD Bill 2013').

[58] Select Committee on the Assisted Dying for the Terminally Ill Bill, *Assisted Dying for the Terminally Ill Bill [HL]* Volumes I, II and III (2004-05, HL 86-I, 86-II and 86-III).

[59] *Report of the Commission on Assisted Dying* (n51) 195.

[60] A Park and E Clery, 'Assisted dying and decision-making at the end of life' in Park A et al (eds), *BSA: the 21st Report* (Sage 2005).

[61] E Clery et al, 'Quickening Death: the euthanasia debate' in A Park et al (eds), NatCen Social Research, *BSA: the 23rd report – Perspectives on a changing society* (Sage 2007).

[62] 'The Times Poll: CATI Fieldwork: July 17th-19th 2009' (Populus).

[63] Chapple (n44) 706.

opinion. In doing so, however, the thesis acknowledges the limitations on terminal prognosis. Clinical evidence shows that physicians are often inaccurate in their estimation of a patient's prognosis and life expectancy, and that assessing the terminal phase is inherently difficult.[64] The limitations on prognosis have also been highlighted in foreign studies.[65] In a 2000 American study on doctors' prognoses for terminally ill patients, the researchers found that physicians are often inaccurate in their prognoses, and that the error is systematically optimistic.[66] Similarly, in a 2001 research paper on clinical predictions of survival, a group of Australian researchers noted that the prognoses in terminally ill cancer patients are far more frequently over-optimistic about life expectancy than they are overly pessimistic.[67] It will be argued that, although the terminal phase of an illness may not be known with absolute certainty, there is a need for an arbitrary definition of 'terminal illness' in the proposed law for physician-assisted suicide, in order to minimise the likelihood of abuse.[68]

Opinion polls also show that there is less public support for making the option of assisted death available to people with non-terminal life-limiting conditions. The 2007[69] and 2010[70] *BSA* surveys both found that more than 80% of the public support assisted dying being made available for people dying of incurable illnesses, but only 45% support assisted dying for people with non-terminal conditions. The July 2009 Populus poll similarly found that of the 85% of respondents who supported assisted suicide under certain circumstances, only 65% were in favour for people with a degenerative condition who were not terminally ill; 56% were in favour of this for people who were suffering extreme pain but who were not terminally ill; 48% were in favour for people with a 'severe physical disability' who were otherwise healthy and 34% for 'people who simply wish to die at the same time as a long-term spouse or partner who has a terminal

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[64] P Glare, N Christakis, 'Predicting survival in patients with advanced disease' in D Doyle et al (eds), *Oxford Textbook of Palliative Medicine* (3rd edn,OUP 2004).

[65] E Chow et al, 'How accurate are physicians' clinical predictions of survival and the available prognostic tools in estimating survival times in terminally ill cancer patients? A systematic review' (2001)13(3) Clinical Oncology 209.

[66] NA Christakis and EB Lamont, 'Extent and determinants of error in doctors' prognoses in terminally ill patients: prospective cohort study' (2000)320 BMJ 469.

[67] Glare et al 'A systematic review of physicians' survival predictions in terminally ill cancer patients' (2003)327 BMJ 195.

[68] LO Gostin, 'Drawing a Line Between Killing and Letting Die: The Law, and Law Reform, on Medically Assisted Dying' (1993)21 J Law Med Ethics 94,98.

[69] Clery (n61).

[70] S McAndrew, 'Religious faith and contemporary attitudes' in A Park et al(eds), NatCen Social Research, *BSA:the 26th Report* (Sage 2010).

illness'.[71] As noted by the Commission's 2012 Report, the results of these opinion polls indicate public concern for those whose lives might be devalued in the eyes of society, by the very fact of such an option being made available to them.[72]

Groups of people considered potentially vulnerable under a law permitting physician-assisted suicide will be identified in this thesis, and safeguards to protect them will also be examined. They include the disabled and the elderly. Those opposed to the legalisation of assisted death often argue that were it to be legalised, the vulnerable may feel pressured to request an assisted death.[73] The argument is that if the vulnerable think that their life is not of value to society,[74] they may be pressured to spare society, or loved ones from the perceived hardship and distress of their care.[75] Care Not Killing ('CNK'), an organisation which campaigns against the legalisation of euthanasia in the UK, believes that any relaxation of the current prohibition against assisted suicide in England and Wales will leave vulnerable people without adequate legal protection, and will forge a mindset that certain lives are less worth living.[76] The thesis will consider the possible impact of a law on physician-assisted suicide for terminally ill patients on the ageing population in England and Wales. The July 2009 Populus poll found that 90% of those aged 65 years and over ('the elderly') felt that assisted suicide should be legalised for people who are terminally ill.[77] Nevertheless, it will be argued that the proposed law should have strict safeguards to protect the elderly who might in turn be vulnerable under such a law.

Depression is another source of vulnerability that will be explored. Studies have found a close relationship between terminal illness, depression and the desire for hastened death. In Ganzini et al's 2000 study of physicians' experiences with Oregon's law on physician-assisted suicide, approximately 20% of requests for physician-assisted suicide

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[71] 'The Times Poll: July 17th-19th 2009' (n62).

[72] *Report of the Commission on Assisted Dying* (n51) 292.

[73] BD Onwuteaka-Philipsen et al, 'Dutch Experience of Monitoring Euthanasia' (2005)331 BMJ 691.

[74] JC D'Oronzio, 'Rappelling on the Slippery Slope: Negotiating Public Policy for Physician-Assisted Death' (1997)6(1) Cambridge Quarterly of Healthcare Ethics 113.

[75] EL Csikai, 'Euthanasia and Assisted Suicide: Issues for Social Work Practice' (1999)31(3) J Gerontological Social Work 49.

[76] Care Not Killing ('CNK') is a UK-based alliance of individuals and organisations established in 2005. It brings together disability and human rights organisations, healthcare and palliative care groups, and faith-based organisations. See <www.carenotkilling.org.uk> accessed 10 June 2013.

[77] 'The Times Poll: July 17th-19th 2009' (n62).

came from depressed patients.[78] Chochinov et al's 1995 Canadian study on the desire for death in the terminally ill similarly showed that a 'serious' desire for death was associated with a diagnosis of depression. The study found that 8.5% of 200 terminally ill patients had a 'serious or pervasive' desire for death. Of these patients, 58.8% had a diagnosis for depression compared with only 7.7% for those patients with no such desire.[79] A similar and more recent study in the UK found 14% of 300 terminally ill participants to have a desire for death, out of which 63.6% had some form of depressive disorder.[80] It will be demonstrated that depression is often undetected by physicians, and that undiagnosed or untreated clinical depression in patients may impair their decision-making capacity. To ensure that a patient's request for assisted death is not affected by depression or any other mental disorder, the thesis includes a mandatory mental health evaluation within its proposed law for physician-assisted suicide.

Those opposing the legalisation of assisted death often argue that palliative care is a viable alternative to assisted death.[81] They argue that good palliative care can adequately relieve the pain and distress of terminally ill patients. Palliative treatment includes comfort care, hospice care and pain-control options.[82] It aims to relieve the symptoms of terminal illness, and focuses on a patient's quality of life.[83] The anti-euthanasia organisation, CNK, promotes more and better palliative care for the terminally ill.[84] The thesis will demonstrate that palliative care is unable to provide all patients with total relief from distressing symptoms.[85] It will be argued that the legalisation of physician-assisted suicide is needed to respond to the predicament of terminally ill patients, whose pain and suffering cannot be relieved by even the best palliative care.

The fear of many terminally ill patients is the possibility of dying in an undignified manner.[86] The thesis will show that a loss of autonomy and personal dignity, and a diminished quality of life are often the more important concerns of those requesting

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[78] L Ganzini et al, 'Physician's experiences with the Oregon Death with Dignity Act' (2000)342 N Engl J Med 557.

[79] HM Chochinov et al, 'Desire for Death in the Terminally Ill' (1995)152 Am J Psychiatry 1185,1189-90.

[80] Price (n45).

[81] D Harris et al, 'Assisted Dying: The Ongoing Debate' (2006)82 Postgraduate Medical Journal 479.

[82] R Korobkin, 'Physician-Assisted Suicide Legislation: Issues and Preliminary Responses' (1998)12 Notre Dame J.L.Ethics & Pub.Pol'y 449.

[83] C Saunders, 'Hospice' (1996)1 Mortality 317.

[84] See CNK (n76).

[85] R Hoffenberg, 'Assisted dying' (2006)6 Clinical Medicine 72.

[86] R Russell, *Freedom to Die: The Legal Aspects of Euthanasia* (Human Sciences Press 1977) 35.

assisted death.[87] Advances in medical technology over recent decades have increased the possibilities for managing and treating the pain and symptoms of the terminally ill. However, medical technology often does nothing to improve a patient's quality of life.[88] Rather, it prolongs the dying process.[89] Suffering and dying may be prolonged to the point where the terminally ill decide that it is no longer worth living.[90] It will be argued that terminally ill patients should be able to make a request for physician-assisted suicide based on a personal assessment of their quality of life. This would be consistent with court decisions allowing the withholding or withdrawal of life-sustaining treatment from incompetent patients, which are similarly based on a judgement of the patient's quality of life.

The thesis will show that English law is also out of step with legal provisions in other jurisdictions around the world.[91] A key factor influencing public opinion of the current law in England and Wales is the laws of those other jurisdictions which permit assisted death in some form. By informing popular debate in England and Wales, these jurisdictions are changing the views of society at large. For this reason, the thesis undertakes a comparative analysis of the laws and legal issues relating to assisted death in six other jurisdictions — the Netherlands, Belgium, Oregon (US), the Northern Territory (Australia), Switzerland, and Germany — to consider alternative provisions which might be adopted in England and Wales. The thesis will assess the impact of their laws on assisted death, and evaluate the efficacy of each jurisdiction's approach to assisted death in the context of their particular cultural and legal background.

One of the main objections against law reform in England and Wales is the so called 'slippery slope' argument — that if assisted death were legalised then it could not be efficiently monitored and controlled and will lead to error, abuse, and the violation of the rights of vulnerable patients.[92] Disability rights organisations in the UK, such as Not

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[87] R Smith, 'A Good Death' (2000)320 BMJ 129.

[88] M Otlowski, 'Active Voluntary Euthanasia: Options for Reform' (1994)2 Med.L.Rev 161.

[89] ibid.

[90] GS Neeley, 'The Constitutional Right to Suicide, the Quality of Life, and the "Slippery-Slope": an Explicit Reply to Lingering Concerns' (1995)28 Akron L.Rev. 53,54.

[91] HM Biggs, 'The Assisted Dying for the Terminally Ill Bill 2004: Will English Law Soon Allow Patients the Choice to Die?' (2005)12 Eur J Health L 43.

[92] RJD George et al, 'Legalised Euthanasia will Violate the Rights of Vulnerable Patients' (2005)331 BMJ 684.

Dead Yet UK[93] and Scope,[94] are opposed to the legalisation of assisted death on this basis. They have expressed concern that even very limited legalisation for a small set of cases would lead to assisted death being practised beyond the group of people for whom it was envisaged. Others argue that legalising assisted suicide may lead to the permissibility of voluntary euthanasia[95] and even to the acceptance of involuntary and non-voluntary euthanasia.[96] They fear that vulnerable groups might become 'targets of non-voluntary euthanasia disguised as physician-assisted suicide'.[97] Glover describes involuntary euthanasia as where a person is assisted to die against their expressed wishes, and non-voluntary euthanasia as where the person being assisted to die cannot express their wishes because of their physical or mental state.[98] The thesis will investigate whether there is evidence to support such 'slippery slope' concerns, and whether safeguards can stringently minimise the risk of such abuse.[99]

The thesis will establish that the present law prohibiting assisted death in England and Wales is unsatisfactory. It will propose a law that permits physician-assisted suicide as a medical option of last resort, to competent patients who are terminally ill. Such patients may make an autonomous request for assisted suicide, if they experience a poor and unacceptable quality of life due to the unbearable suffering caused by their terminal illness. The proposed law will include strict legal safeguards to protect potentially vulnerable people, and avoid other potential abuse of the law.[100]

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[93] Not Dead Yet UK (NDYUK) is a network of disabled people in the UK, who oppose the legalised killing of disabled people. All those involved are disabled people including people with physical and sensory impairments, learning difficulties, and mental distress. See 'About Not Dead Yet UK' <www.notdeadyetuk.org/notdeadyet-about.html> accessed 28 July 2013.

[94] A UK disability charity. See <www.scope.org.uk> accessed 28 July 2013.

[95] Refer to explanation in n7.

[96] Csikai (n75)

[97] CH Pailet, 'Comment: Abortion and Physician-Assisted Suicide: Is There a Constitutional Right to Both?' (2006)8 Loyola J Public Interest Law 45,66.

[98] J Glover, *Causing death and saving lives* (Penguin 1977).

[99] Otlowski (n88).

[100] This framework is similar to the one proposed by Dignity in Dying, a British pro-assisted death lobby group. See 'The law is not working' (*Campaign for Dignity in Dying*) <www.dignityindying.org.uk/assisted-dying/law-not-working.html> assessed 14 May 2013.

1.4 Research questions

The five research questions addressed in this thesis are as follows:

i) Is the current law on assisted death in England and Wales satisfactory? In addressing this research question, the thesis will examine whether the law meets the needs of society in general and of individuals who competently decide that they do not wish to continue living, whether the law is consistent and coherent, and whether the law is legally and morally defensible.

ii) Have recent legal developments on assisted death addressed the needs of society and the concerns of those seeking an assisted death in England and Wales? In addressing this research question, consideration is given to the impact of the House of Lords decision in *Purdy*,[101] the DPP's Policy,[102] the Court of Appeal decision in *Nicklinson*,[103] the present debate on the legalisation of assisted death, the recent Bills on 'assisted death' introduced in Parliament,[104] and the influence of the laws of other jurisdictions.[105]

iii) Can a person's 'quality of life' determine whether they should have an assisted death? In addressing this research question, the extent to which 'quality of life' has been an influence on legally permitted end-of-life medical decisions will be considered. Court decisions where life-sustaining treatment has been withdrawn or withheld from incompetent patients will be examined, to determine whether the 'best interests' assessment by the courts and doctors is in effect a quality of life judgement.

iv) Would a law permitting assisted death for a restricted group of people lead to assisted death being practised beyond that group? This question is concerned with whether legalisation would, either likely or inevitably, lead to an unintended further extension of the law — euphemistically described as a descent on the 'slippery slope'. In addressing this research question, the assisted death laws of the selected jurisdictions are examined to determine whether the

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[101] *Purdy* (HL)(n31).

[102] DPP's Policy (n34).

[103] *Nicklinson* (CA)(n10).

[104] e.g. Assisted Dying for the Terminally Ill HL Bill (2003-04) 17 (n48), Assisted Dying HL Bill (2013-14) 24 (n57).

[105] i.e. the Netherlands, Belgium, Oregon (US),the Northern Territory (Australia), Switzerland,and Germany.

slippery slope argument is indeed a legitimate concern, and if so, whether effective safeguards could be successfully implemented to protect vulnerable members of society.

v) If the law on assisted death is to be reformed in England and Wales, what should the scope of the change be and how should the proposal for law reform be drafted? In addressing this research question, recent proposals for change in England and Wales, and the laws on assisted death of the other jurisdictions will be examined to inform potential reforms, and provide a valuable reference point.

An overview of the structure of the thesis, and the methodologies employed by this thesis will now follow.

1.5 Structure of thesis

The thesis is comprised of seven chapters. The chapters are described briefly as follows.

Chapter One introduces the topic of the thesis. It sets out the problems with the current law which governs assisted death in England and Wales, and the principal sources of controversy in the debate on the potential legalisation of assisted death. The chapter explains the aims and objectives of the thesis. It outlines the research questions that are to be addressed, and sets out the structure of the thesis. It also explains the methodology that is adopted to answer the research questions.

Chapter Two sets out the present law on assisted death in England and Wales. It establishes that the current English law on assisted death is legally and morally inconsistent, because whilst assisted death is illegal, physicians are legally permitted to carry out certain end-of-life medical decisions. These are medical decisions involving a ‘double effect’ and the ‘acts and omissions’ distinction. The chapter considers the recent developments in English law concerning assisted death. These include the cases of Diane Pretty,[106] Debbie Purdy[107] and Tony Nicklinson,[108] the DPP’s decision in the case of Daniel James, and the DPP’s Policy.[109] The chapter also examines recent attempts made to legalise assisted death in England and Wales. These include the ADTI Bill

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[106] *Pretty* (HL)(n41).

[107] *Purdy* (HL)(n31).

[108] *Nicklinson* (CA)(n10).

[109] DPP’s Policy (n34).

2004,[110] and the AD Bill 2013[111]. The recommendations of the 2004 Select Committee,[112] and the Commission's 2012 Report[113] will also be evaluated.

Chapter Three examines the social and ethical influences which have affected the development of the law on assisted death in England and Wales to-date. It considers whether English law meets the needs of society, and whether the law is consistent and morally defensible. The social influences examined are religion, a rise in individualism, and an ageing of the population. The ethical influences considered are sanctity of life, a right to self-determination, professional ethics, the doctrine of double effect, the concept of 'quality of life', paternalism, and an increasing scarcity of healthcare resources. Theories which offer a framework for such ethical influences are also considered. These include the four principles of medical ethics (respect for autonomy, non-maleficence and beneficence, and justice in medical care) which determine the ethical duties that physicians owe to their patients, and the ethical measures of consequentialism and deontology which are used to assess the morality of actions. Other influences affecting the debate on the legalisation of assisted death are also discussed. These include public trust in physicians, advances in medical technology, palliative care, concerns over patient dignity, concerns over a slippery slope, concerns for vulnerable members of society, the laws on assisted death of other jurisdictions, and the role of the media. The chapter examines the impact of these influences on both the law on assisted death, and on legally permitted end-of-life medical decisions.

Chapter Four examines whether a person's 'quality of life' can be used to determine whether they should be permitted to receive an assisted death. It shows that considerations of quality of life have been relevant to end-of-life medical decisions made to-date. The chapter considers the extent to which English law has allowed quality of life to influence decisions involving the withdrawal or withholding of life-sustaining treatment in the 'best interests' of incompetent patients. The chapter also considers the difficulties of assessing a patient's quality of life.

Chapter Five examines the laws which govern euthanasia and assisted suicide in six other jurisdictions — the Netherlands, Belgium, Switzerland, Germany, the Northern

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[110] ADTI Bill 2004 (n48).

[111] AD Bill 2013 (n57).

[112] 2004 HL Select Committee Report Volumes I, II and III (n58).

[113] *Report of the Commission on Assisted Dying* (n51).

Territory (Australia) and Oregon (US). Although the Netherlands, Belgium, Switzerland and Germany have civil law systems, and the Northern Territory and Oregon have common law systems, the chapter identifies common themes in these legal regimes. Assisted suicide is currently expressly provided for by law in the Netherlands, Switzerland, and Oregon, whilst euthanasia is legalised only in Belgium and the Netherlands. In the Northern Territory, euthanasia and assisted suicide were both temporarily legalised from July 1996 until March 1997. Except for Switzerland and Germany, in all these jurisdictions, assisted death has been carried out by physicians. There is no law that expressly permits assisted suicide in Germany, neither is there any law that explicitly forbids it. Except for physicians, who are disallowed from assisting in deaths, anyone may assist in suicides in Germany. Chapter Five identifies features from these foreign laws which could potentially resolve issues of debate in England and Wales. It considers the social and ethical influences affecting these laws, and examines the extent to which 'quality of life' has been an influence on end-of-life medical decisions in these foreign jurisdictions. The chapter also examines whether the laws in each of these jurisdictions have been effective in response to their initial call for reform, and whether they have been subject to abuse.

Chapter Six examines the 'slippery slope' argument. It investigates whether there is evidence from the Netherlands, Belgium and Oregon to support the slippery slope argument. Examples of slippery slope concerns which are looked for, include an expansion of circumstances for lawful euthanasia, and a disregard for the current regulations by physicians and enforcement authorities. The chapter considers whether there have been risk factors introduced into any of these jurisdictions which constitute potential slippery slope 'mechanisms'. It examines whether there is evidence to support a slippery slope argument that a law which permits voluntary euthanasia will lead to a stronger likelihood of non-voluntary euthanasia taking place. The chapter also investigates whether the current English law concerning the withdrawal and withholding of life-sustaining treatment provides support for similar slippery slope concerns with regard to such end-of-life medical decisions.

Chapter Seven recapitulates the issues discussed across the entire thesis. It examines whether the aims and objectives outlined in section 1.3 above have been met, and whether the research questions set out in section 1.4 have been answered. The chapter also makes specific proposals for law reform in England and Wales. It considers a law on physician-assisted suicide for competent patients who are terminally ill and suffering unbearably, and experiencing a poor and unacceptable quality of life. The chapter also considers strict safeguards to prevent abuse of the law, and to protect vulnerable members of society.

1.6 Research Methodology

To answer the research questions stated in section 1.4, the research methodology adopted in this thesis involves three methods of research – a socio-legal approach, a doctrinal evaluation, and a comparative law analysis. As Chynoweth observes, legal enquiry has begun to move in the direction of inter-disciplinary research, such as the socio-legal approach of this thesis.[114] The research methodology and its methods are addressed separately below.

1.6.1 *Socio-legal approach*

According to a socio-legal approach, the analysis of law is directly linked to the analysis of the social situation to which the law applies.[115] As asserted by Cotterrell, true legal scholarship must entail a sociological understanding of law.[116] To broaden the understanding of the law, it is to be seen as an entirely social phenomenon that must be understood empirically and systematically.[117] Under a socio-legal approach, legal institutions, like any other social institutions, cannot be understood without seeing the entire set of interacting relations of which they are constituted, and the environment in which they function.[118] Schiff argues that the methodology of 'sociology of law' does not start with the primacy of legal rules or laws, or of a legal system. Instead, the methodology is determined by an initial understanding of society, or of the social system, with the aim of analysing social structures and social institutions generally.[119]

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[114] P Chynoweth, 'Legal research' in A Knight and L Ruddock (eds), *Advanced Research Methods in the Built Environment* (Blackwell Publishing 2008) 28,30.

[115] DN Schiff, 'Socio-Legal Theory: Social Structure and Law' (1976)39 MLR 287,287.

[116] R Cotterrell, 'Why Must Legal Ideas be Interpreted Sociologically?' (1998)25(2) J.L.& Soc'y 171.

[117] ibid 183.

[118] SS Sibley, 'Ideology, Power and Justice', in BG Garth and A Sarat (eds), *Justice and Power in Sociolegal Studies* (Northwestern University Press 1998) 273.

[119] Schiff (n115) 294.

A socio-legal approach as described above has been used to examine the social and ethical influences that currently affect the debate on the legalisation of assisted death in England and Wales. As will be noted in Chapter Three, these social and ethical influences include i) sanctity of life, ii) respect for autonomy, iii) quality of life, iv) concerns over patient dignity, and v) societal interests that may be grounded in moral, philosophical or religious traditions.[120] The thesis will consider whether a person's autonomy should override the doctrine of sanctity of life, and whether 'quality of life' should be used to inform assisted death.[121] Within the social and legal debate surrounding assisted death, it will be demonstrated that 'suicide tourism' cases have also had an impact on the English legislature, particularly where family or friends 'assist' by making travel arrangements and accompanying their loved ones abroad for an assisted suicide.[122] Studies and surveys which have assessed the laws on assisted death in the selected jurisdictions (the Netherlands, Belgium, Oregon (US), the Northern Territory (Australia), Switzerland, and Germany) are also examined in Chapters Five and Six, to inform the thesis. These studies also raise issues associated with comparative law, which are considered in section 1.6.3 below.[123]

1.6.2 *Doctrinal research*

The doctrinal research method is characterised by the study of legal texts, and for this reason is often described colloquially as 'black-letter law'.[124] 'Doctrine' has been defined as '[a] synthesis of various rules, principles, norms, interpretive guidelines and values'.[125] The doctrinal research method is a two-part process because it involves first locating the primary sources of the law, and then interpreting and analysing the text to establish the nature and parameters of that law.[126]

Chapter Two will examine the law on assisted death and legally permitted end-of-life medical decisions in England and Wales. This includes the decision of the House of

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[120] TS Jost, 'Comparative and International Health Law' (2003)14 Health Matrix 141.

[121] This will be discussed in chs2,3,and 4.

[122] S Ost, 'The De-Medicalisation Of Assisted Dying: Is A Less Medicalised Model The Way Forward?' (2010)18 Medical Law Review 497,498,515.

[123] E Orucu, 'Methodology of comparative law', in J Smits (ed), *Elgar Encyclopaedia of Comparative Law* (Edward Elgar Publishing 2006) 442.

[124] Chynoweth (n114) 29.

[125] T Hutchinson, *Researching and Writing in Law* (3rd edn, Reuters Thomson 2010) 38.

[126] T Hutchinson and N Duncan, 'Defining and Describing What We Do: Doctrinal Legal Research' (2012)17(1) Deakin LR 83.

Lords in *Purdy*,[127] and the DPP's Policy[128]. Recent Bills proposing to legalise assisted death will also be examined.[129] Chapter Five will analyse assisted death legislation in other selected jurisdictions,[130] to consider whether England and Wales can learn any lessons from their experiences.

This thesis' doctrinal analysis inevitably raises issues as to the purpose and context of the law. There is thus an inescapable 'shading' of doctrinal analysis into socio-legal issues. Legal rules are normative in character as they dictate how individuals ought to behave.[131] However, they make no attempt to either explain or understand human behaviour.[132] The socio-legal approach is acknowledged by Chynoweth as having a place in doctrinal research. He notes that in practice, doctrinal analysis usually makes at least some reference to other external factors. He explains, for example, that an uncertain or ambiguous legal ruling can often be more easily interpreted when viewed in its proper historical or social context, or when one has an adequate understanding of the setting or circumstances to which it relates.[133] Thus, it is important to build on doctrinal research conclusions by using sociological or other 'outsider' perspectives.[134]

Further, whilst legal doctrine is the description and the systematisation of the law in one specific legal system, comparative law (as explained in the following section) is the comparing of legal systems.[135] Together with statute law, case law and customary law, legal doctrine is an object of the comparative study.[136]

1.6.3 *Comparative law*

Comparative law involves the investigation of legal rules, structures, approaches and techniques in more than one system or society.[137] Comparative law is undertaken in this

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[127] *Purdy* (HL)(n31).

[128] DPP's Policy (n34).

[129] See nn48,57.

[130] See n105.

[131] H Kelsen, *The Pure Theory of Law* (M Knight tr, University of California Press 1967).

[132] Chynoweth (n114) 30.

[133] ibid 30.

[134] Hutchinson and Duncan (n126).

[135] M Van Hoecke and M Warrington, 'Legal Cultures, Legal Paradigms and Legal Doctrine: Towards a New Model for Comparative Law' (1998)47 ICLQ 495.

[136] ibid.

[137] A Watson, 'Comparative Law and Legal Change' (1978)37 Cambridge L.J. 313, 317.

thesis to identify common themes on assisted death across the legal systems of selected jurisdictions – the Netherlands, Belgium, Switzerland, Germany, the Northern Territory (Australia), and Oregon (US). It is used to test whether a particular notion about a law is true across different systems, and to determine whether a law reflects a consistent manner of dealing with behaviour across states, or a local idiosyncrasy.[138] By examining the law on assisted death of other jurisdictions, we can see how foreign legal systems approach and resolve common problems.[139]

The Netherlands, Belgium, Switzerland, and Germany have civil law systems, whilst England and Wales, Australia and the United States have common law systems.[140] Civil law systems are based on a code which contains the laws that regulate society.[141] In common law systems, the common law as a body of law consists of all the rules that can be generalized out of judicial decisions.[142] There is also legislation in common law systems.[143] This consists of particular rules intended to control certain factual situations, and are thus specified with considerable detail compared to judicial decisions.[144]

A crucial difference between civil law systems and common law systems is that a civil law system's code generally states new law and abolishes the previous law on the same area, whereas statutes in common law systems often supplement or codify pre-existing case law rather than replacing such law.[145] The legislature in a common law system may selectively enact individual amendments to a law due to a changing environment or incidents unforeseeable at the time of a statute's enactment.[146] This is because 'courts are not capable of writing speedily enough most of the rules that a modern society apparently needs'.[147] Over time, the legislature in common law systems develops an extensive body of statutes.[148] This development of statutes as a source of law in common

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[138] R Cryer et al, *Research Methodologies in EU and International Law* (Hart Publishing 2011),28.

[139] J Hill, 'Comparative Law, Law Reform and Legal Theory' (1989)9 Oxford J.Leg.Stud 101,102.

[140] D Mendelson and TS Jost, 'A Comparative Study of the Law of Palliative Care and End-of-Life Treatment' (2003)31 Journal of Law, Medicine & Ethics 130.

[141] J Dainow, 'The Civil Law and the Common Law: Some Points of Comparison' (1967)15 Am.J.Comp.L 419,424.

[142] ibid 424.

[143] ibid 425.

[144] ibid 425.

[145] JH Merryman, *The Civil Law Tradition: An Introduction to the Legal Systems of Western Europe and Latin America* (2nd edn Stanford University Press 1985) 7,27,32.

[146] K Schadbach, 'The Benefits of Comparative Law: A Continental European View' (1998)16 Boston University International Law Journal 331,377.

[147] G Calabresi, *A Common Law for the Age of Statutes* (Harvard University Press 1982) 163.

[148] Schadbach (n146) 376.

law systems supports the use of statutory analogies for comparative research purposes.[149] As Schadbach observes, the 'age of statutes'[150] demands that the common law methodology be augmented by civil law methodologies elaborated in statutorily-based systems.[151]

A civil law system, in which the law-making role of a judge is limited, assumes judges interpret a statute rather than create substantive law.[152] However, in a common law system, whenever a statute does not specifically address a set of facts, the application of the common law is the default rule.[153] The common law systems direct courts, when faced with statutory language that is silent on an issue, to any prior (common) law on the issue, or to assume that the issue is left for common law judicial decision making.[154]

Comparative law as a research method is often used to propose reforms to a law,[155] as comparisons provide legislators with new regulatory and conceptual ideas.[156] As noted by Maine in 1871, 'The chief function of comparative jurisprudence is to facilitate legislation and the practical improvement of the law.'[157] Similarly, Zweigert and Kötz assert more recently, '[C]omparative law is an *école de vérité* which extends and enriches [sic] the "supply of solutions" and offers the scholar of critical capacity the opportunity of finding the "better solution" for his time and place.'[158] Thus, comparative law is employed in this thesis as an aid to reform the law on assisted death in England and Wales.[159] Knowledge of the different laws in the selected jurisdictions extends to the statutory requirements, qualifications or safeguards which could potentially resolve issues of debate in England and Wales.[160] Domestic law cannot always adequately deal with problems in its own legal system.[161] Comparative law enlarges the 'supply of solutions'. The thesis considers whether England and Wales can learn any lessons from

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[149] ibid 376.

[150] Calabresi (n147).

[151] Schadbach (n146) 377.

[152] Merryman (n145) 36,78,81-83.

[153] Schadbach (n146) 375.

[154] ibid 375.

[155] G Frankenberg, 'Critical Comparisons: Re-thinking Comparative Law' (1985)26 Harv.Int'l L.J. 411,413.

[156] Schadbach (n146) 357.

[157] HS Maine, *Village Communities in the East and West: Six lectures delivered at Oxford* (J Murray 1871) 4.

[158] K Zweigert and H Kötz, *An Introduction to Comparative Law Vol I* (T Weir tr, 2nd edn, OUP 1987) 15.

[159] WJ Kamba, 'Comparative Law: A Theoretical Framework' (1974)23 ICLQ 485,497.

[160] R Sacco, 'Legal Formants: A dynamic Approach to Comparative Law (Instalment I of II)' (1991)39(1) Am.J.Comp.L. 1.

[161] Schadbach (n146) 350.

the experiences of these selected jurisdictions, noting that they do not always share common philosophical and religious traditions.[162] For this reason, the adoption of any principles or rules from these selected jurisdictions in England and Wales requires careful consideration to maximise the prospect of success.

As it is necessary to examine and evaluate a foreign legal concept before adopting it domestically,[163] comparative law provides an increased and deepened understanding of both foreign and domestic laws.[164] In addition to gaining knowledge of other countries' laws, comparing legal institutions and concepts is an avenue to new insights about one's own legal system.[165] Comparative law may challenge one's understanding of the domestic system through the use of the different rules and approaches of the foreign system.[166]

Comparative law is about 'legal transplants' – the desirability and practicality of borrowing from another legal system.[167] The methodology reveals the viability of a transplant of one system's laws into another legal system.[168] As such, it is important to understand the foreign rules, institutions and cultures of the selected jurisdictions, and assess the prospects for a good 'fit' within England and Wales.[169] According to Schadbach, the knowledge of alternative answers to common legal problems inevitably provides novel ways to understand and solve problems in one's own legal system.[170] The acceptance of a foreign law or legal concept is more likely to occur where the compared legal systems share common socio-cultural, economic, or political factors.[171] The more comparable two legal cultures are, the greater the benefit one receives in relation to one's own system.[172] It would be a futile effort to transplant laws to a country with a completely different cultural and social background.[173]

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[162] Jost (n120).

[163] Schadbach (n146) 357.

[164] Frankenberg (n155) 413.

[165] Schadbach (n146).

[166] ibid 344.

[167] Watson (n137) 318.

[168] Schadbach (n146) 344,392.

[169] Jost (n120).

[170] Schadbach (n146) 335.

[171] ibid 362.

[172] C Osakwe, 'Recent Development' (1988)62 Tul.L.Rev 1507,1508 (reviewing Zweigert and Kötz (n158)).

[173] O Kahn-Freund, 'On Uses and Misuses of Comparative Law' (1974)37 MLR 1,7,27.

It is, however, difficult to set up a common methodology of comparative law.[174] The difficulty is that of comparing ‘like with like’,[175] due to the legal and cultural differences between the legal systems of the selected jurisdictions.[176] Such differences may limit the ability to draw inferences from these jurisdictions, as to what would happen in England and Wales.[177] A further challenge is that we see other systems, as we see other cultures, through preconceptions of our own.[178]

In this thesis, comparative research is carried out within the common law system by examining the assisted death legislation in the Northern Territory and Oregon. This is referred to by commentators as intra-systematic comparison.[179] The disadvantage of an intra-systematic comparison, according to Zweigert and Kötz, is that often such a comparison does not offer the distance necessary to gain new insights into one’s own system.[180] However, Schadbach observes that the main advantage of an intra-systematic comparison is that solutions are easier to transfer, since the ‘host body’ would be more receptive to the ‘legal transplant’.[181] It is accepted that such intra-systematic comparisons are still valuable, as they enable one to learn from another system’s mistakes, flaws or weaknesses and thus improve on refining the law.

Comparisons are also made in this thesis with the assisted death laws in four civil law systems – the Netherlands, Belgium, Switzerland and Germany. This is known as an extra-systematic comparison.[182] The difficulty with an extra-systematic comparison is that the distinctions between a common law system and a civil law system have to be considered when carrying out such comparative research. For example, civil law systems often distinguish euthanasia as a criminal offence which is distinct from other forms of wilful homicide.[183] Euthanasia is recognised as ‘homicide upon request’ with a less severe sentence, as the consent or request by the deceased is regarded as a

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[174] Schadbach (n146) 378.

[175] Cryer (n138) 28.

[176] P De Cruz, *Comparative Law in a Changing World* (Cavendish Publishing Limited 1995) 211.

[177] P Lewis, ‘The Empirical Slippery Slope from Voluntary to Non-Voluntary Euthanasia’ (2007)35(1) J Law Med Ethics 197.

[178] L Zedner, ‘In Pursuit of the Vernacular: Comparing Law and Order Discourse in Britain and Germany’ (1995)4 Social & LS 517,519.

[179] Schadbach (n146) 362.

[180] Zweigert and Kötz (n158) 13-14.

[181] Schadbach (n146) 362.

[182] ibid 362.

[183] LT Nerland, ‘A Cry for Help: A Comparison of Voluntary, Active Euthanasia Law’ (1989-1990)13 Hastings Int'l& Comp.L.Rev. 115.

mitigating factor.[184] In contrast, euthanasia is classified as murder in all common law systems. A further distinction is that in civil law systems, motive is an integral element in determining 'culpability' for a crime. However, under common law, motive is only an evidentiary factor.

In conclusion and despite the challenges noted above, it is argued that there are three main reasons why the use of a comparative law research method is beneficial to this thesis. First, the experience of the other systems of law is valuable not only in suggesting a foreign legal institution or law as a model or guide, but also in showing what laws to avoid.[185] As Tallon states:

> [The] aim [of comparative analysis] is not to find a foreign institution which could be easily copied, but to acquire ideas from a careful survey of similar foreign institutions and to make a reasonable transportation of those which may be retained, according to local conditions.[186]

The second reason which calls for the employment of the comparative law research method, addresses the technique of drafting legislation.[187] '[A]ny intelligent group of draftsmen…will consider similar legislation in other states…and will not confine their efforts necessarily to a restatement of what they conceive to be "the law" of their jurisdiction.'[188] The third reason is concerned with the question of practicability and enforceability of the proposed law.[189] In this regard, experience gained by one legal system as to the effectiveness of some legal solutions may be most valuable to another.[190]

1.6.4 *Conclusions on research methodology*

Although the doctrinal research method would involve mainly a qualitative evaluation, the socio-legal approach in this thesis allows for a broader evaluation of the legal and ethical arguments and influences on the law of assisted death. The comparative law

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[184] MD Sayid, 'Euthanasia: A Comparison of the Criminal Laws of Germany, Switzerland and the United States' (1983) 6 Boston Coll.Int'l& Comp.L.Rev. 553, 555.

[185] Kamba (n159) 496.

[186] Tallon, 'Comparative Law: Expanding Horizons' (1969) 10 J.Soc.Pub.T.L. 265,266.

[187] Kamba (n159) 497.

[188] Morrow, 'Comparative Law in Action' (1951)3 J.Leg.Ed 403.

[189] Kamba (n159) 497.

[190] ibid 497.

research method allows further for a quantitative evaluation based on the results of surveys and studies conducted by other researchers (i.e. secondary sources). By applying a combination of a socio-legal approach, the doctrinal and comparative law research methods, this thesis adopts an inter-disciplinary approach to its research. These methods not only complement each other, but the combination reduces the chance of error or bias. This allows for a better understanding of the debate, and bolsters confidence in the findings and answers to the research questions.

The thesis reflects the law as at 1 January 2014.

Chapter 2: The Development of English Law

2.1 Introduction

This chapter will set out the scope of the present law on assisted death[1] in England and Wales. It will also consider the recent developments on assisted death that have had an impact on society. Such developments include the cases of Diane Pretty and Debbie Purdy, the DPP's decision not to prosecute the parents of Daniel James, the DPP's Policy, and the Court of Appeal decision in Tony Nicklinson's appeal. It will be demonstrated that these legal developments have been strongly influenced by the ethical principle of 'personal autonomy'.

The chapter will examine the limits and problems with the current law on assisted suicide. It will assess the implications of the DPP's Policy, both in respect of key public interest factors specified by the policy and the wider implications of such a policy on the law. The chapter will show that the clarifications provided by the DPP's Policy are unsatisfactory, and that in spite of assisted suicide being a crime in England and Wales, the DPP's Policy effectively de-criminalises 'compassionate' assisted suicides. Overall, it will be demonstrated that the recent developments in the law on assisted suicide are inadequate with regard to the needs of those who competently decide to end their lives.

In relation to end-of-life issues, the chapter will show further aspects in which English law is unsatisfactory. Although assisted death is illegal, physicians are legally permitted to make end-of-life medical decisions involving a 'double effect', or which fall within the 'acts and omissions' distinction in England and Wales. The chapter will analyse the legal framework surrounding the doctrine of 'double effect', and the withdrawal and withholding of life-sustaining treatment from incompetent patients. It will be demonstrated that whilst English law recognises a person's right of autonomy to refuse life-sustaining treatment and to die from such a refusal, it denies a person a right of autonomy to obtain lethal medication to end their life. To inform the potential law reform agenda for England and Wales, the chapter will also consider Bills which have been recently introduced into Parliament to legalise assisted death for the terminally ill. The chapter will review the recommendations of the House of Lords' Select

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[1] 'Assisted death', defined in section 1.1.

Committee's Report on the Assisted Dying for the Terminally Ill Bill 2004, and the recommendations of the 2012 Report of the Commission on Assisted Dying.

In setting out the current scope of the laws in England and Wales, the chapter will firstly examine the laws governing euthanasia and assisted suicide.

2.2 Current laws governing assisted death

2.2.1 *Euthanasia*

Euthanasia, as defined in Chapter One,[2] is not expressly provided for by English law. However, pursuant to the Homicide Act 1957, euthanasia is prohibited under the law of murder and manslaughter. Nevertheless, in certain circumstances, non-voluntary euthanasia[3] through the withholding or withdrawing of life-sustaining treatment from incompetent patients is lawfully permitted. This is demonstrated below in section 2.3.3.

2.2.2 *Assisted suicide*

Assisted suicide has been a crime in England and Wales since 1861.[4] Despite suicide and attempted suicide ceasing to be crimes with the passing of the SA 1961, assisted suicide remains a crime under section 2(1) of the Act.

Section 2(1) originally provided that any person who 'aids, abets, counsels or procures the suicide of another, or an attempt by another to commit suicide' is liable for up to 14 years imprisonment. Subsequently, to address the emergence of internet websites giving encouragement or assistance with acts of suicide, the Coroners and Justice Act 2009 amended section 2(1) in February 2010 to extend its coverage.[5] It now provides that a person commits an offence if they do an act 'capable of encouraging or assisting the suicide or attempted suicide of another person', and that act 'was intended to encourage or assist suicide or an attempt at suicide'.

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[2] 'Euthanasia', defined in section 1.1.

[3] 'Non-voluntary euthanasia' (text to ch1 n98).

[4] *R v Croft* [1944] 1 KB 295,296.

[5] Coroners and Justice Act 2009 sub-s59(2). See also, Ministry of Justice, *Encouraging or Assisting Suicide: Implementation of section 59 of the Coroners and Justice Act 2009* (Circular 2010/03) 28 January 2010.

It is argued that by decriminalising suicide, English law has taken account of society's right to 'personal autonomy'[6] and 'self-determination'[7]. This right of individuals to personal autonomy was described by Hedley J in the case of *Re Z*, 'a competent person is entitled to take their own decisions on these matters and that ... person alone bears responsibility for any decision so taken. That is the essence of ... self-autonomy'.[8] By maintaining assisted suicide as a crime, it is contended that the ethical doctrine of sanctity of life[9] has been given predominance over autonomy in assisted suicide cases in England and Wales. Considering that an act of assisted suicide requires the involvement by others, lawmakers may have given precedence to the need to protecting society as a whole and its most vulnerable members. There is, therefore, a conflict of ethical influences in English law, between 'personal autonomy' and 'self-determination' on the one hand, and 'sanctity of life' and 'protecting society' on the other.

It is contended that one's prospect of being prosecuted for assisted suicide in England and Wales lacks sufficient certainty. Whilst the offence of assisted suicide under the SA 1961 is clear, whether or not a person is likely to be prosecuted for this offence is far from clear. Section 2(4) of the SA 1961 provides that 'no proceedings shall be instituted for an offence under [section 2(1)] except by or with the consent of the [DPP]'. Thus, there are instances of assisted suicide that are not culpable. As observed by Hedley J in *Re Z*:

> Although not unique, [the requirement for the DPP's consent] is rare and is usually found where [P]arliament recognises that although an act may be criminal, it is not always in the public interest to prosecute in respect of it.[10]

According to Hedley J's judgment, '[Parliament] has committed to the DPP the discretion as to whether to permit a prosecution.'[11] Despite the potential incoherence in the law by including such a discretion, the following reasons provided by Tur, and by Lord Lane CJ in *R v Hough*, for its inclusion in section 2(4) are compelling. Tur argues that section 2(4) avoids prosecution for assisted suicides that are morally justified, 'in

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[6] See section 3.3.4.

[7] See section 3.3.2.

[8] *Re Z* [2004] EWHC 2817 [21].

[9] See section 3.3.1.

[10] *Re Z* (n8)[14].

[11] ibid [19].

which conviction would be seriously absurd or grossly unjust'.[12] Lord Lane CJ says, 'in terms of gravity [the offence of assisted suicide] could range from the borders of cold-blooded murder down to the shadowy area of mercy killing or common humanity'.[13]

Today, prosecutors are faced with assisted suicide cases that relate to the phenomenon of 'suicide tourism'. Lord Neuberger, in the 2009 case of *Purdy* (discussed below), described 'suicide tourism' as:

> difficult and tragic cases where a loving relative assists a person, who is of sound mind and determined to end her life, to travel abroad to achieve her wish in a country where assisting suicide is not unlawful…[in such cases the relative] will often be a relatively reluctant participator, and will often be motivated solely by love and/or sympathy.[14]

Lord Hope in *Purdy*, however, made clear that it is still an offence under section 2(1) of the SA 1961 for someone to assist another to travel to Switzerland or anywhere else where assisted suicide is lawful in order for the latter to obtain an assisted death.[15] Police investigations have been carried out on the role and involvement of several people in the assisted suicides of loved ones abroad, yet no charges or court proceedings have ever been brought under section 2(1).[16] It is argued that the phenomenon of 'suicide tourism' has created doubt in the law on assisted suicide and undermined society's respect for this law.

An examination of four high profile English cases – Diane Pretty, Daniel James, Debbie Purdy, and Tony Nicklinson – will illustrate that the current law on assisted suicide is inadequate and fails to meet the needs of English society.

– *Diane Pretty*

Diane Pretty had terminal motor neurone disease, 'a progressive degenerative illness from which she [had] no hope of recovery'.[17] She did not want to live in an undignified

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[12] R Tur, 'Legislative Technique and Human Rights: The Sad Case of Assisted Suicide' (2003) Crim.L.Rev 3.

[13] *R v Hough* (1984) 6 CrAppR (S) 406,407.

[14] *Purdy* (HL) (ch1 n31) [97],[102].

[15] ibid[27].

[16] J Shaw, 'News and Views: Recent Developments in the Reform of English Law on Assisted Suicide' (2009)16 Eur J Health L. 333,338.

[17] *Pretty* (HL) (ch1 n41) [1].

and unbearable condition towards the end of her life, as was her prognosis.[18] Pretty's husband was unsuccessful in obtaining advance immunity from prosecution, if he assisted her to travel to Dignitas. Pretty, too, failed in her legal action to have the Suicide Act declared incompatible with the European Convention on Human Rights ('ECHR'). In dismissing Pretty's case, the House of Lords found that, *inter alia*, i) Article 2 of the ECHR[19] could not be interpreted as conferring a right to self-determination[20] in relation to death, and ii) since the Executive has no power to dispense with laws without the consent of Parliament, the DPP had no power to grant such an advance immunity from prosecution.[21]

Pretty then took her case to the European Court of Human Rights ('ECtHR').[22] The ECtHR held that Pretty's personal autonomy,[23] and her 'right to private life' under Article 8(1) of the ECHR, encompass a right to make a decision to end her own life.[24] However, the ECtHR also found that the infringement of Pretty's right to private life was justified under Article 8(2).[25] The ECtHR held that the 'right to private life' does not include 'an absolute right to die', and therefore the State is not required to allow or facilitate a person's death.[26] The ECtHR stated that it would be a threat to the rule of law if individuals were granted exemptions from the law, and the gravity of assisting in someone else's suicide was serious enough that the DPP's refusal to grant advance immunity was not unreasonable.[27] The ECtHR held that any arguments premised on respect for a patient's autonomy were outweighed by the State's interest in 'preserving life and protecting the vulnerable'.[28]

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[18] B Hale, 'A Pretty Pass: When Is There a Right to Die?' (2003)1 Common Law World Review 1,2.

[19] Everyone's right to life shall be protected by law.

[20] See section 3.3.2.

[21] *Pretty* (HL) (ch1 n41) 800-801.

[22] Pretty argued that the decisions of the English courts had violated five articles of the ECHR protecting her right to die, her right to be free of inhuman or degrading treatment, her right to privacy, her freedom of conscience, and her right not to be discriminated against. *Pretty v United Kingdom* (2002)35 EHRR 1,39.

[23] See section 3.3.4.

[24] *Pretty* (ECtHR) (n22) 36-37.

[25] ECHR art 8(2) states that there shall be no interference by a public authority with the exercise of this right except in the interests of national security, public safety, or the economic well-being of the country, for the prevention of disorder or crime, for the protection of health or morals, or for the protection of the rights and freedoms of others.

[26] *Pretty* (ECtHR) (n22) 37.

[27] ibid 39.

[28] *Pretty* (ECtHR) (n22) 48. Pretty died of her condition a few weeks after her appeal to the ECtHR failed. See section 3.4.6 for 'protecting the vulnerable'.

It is concluded that the DPP's refusal to grant advance immunity to Pretty's husband was necessary to upholding the 'sanctity of life',[29] and thus safeguarding the general value of human life and protecting the rights of the vulnerable in society.[30] It is further concluded that these are the very reasons why Parliament is reluctant to legalise assisted death in England and Wales.

– *Daniel James*

Daniel James, a 23 year old rugby player, suffered from tetraplegia[31] after sustaining a spinal injury in a rugby accident.[32] After his third failed suicide attempt, James decided to end his life at Dignitas.[33] James' parents assisted with his correspondence with Dignitas, organised his flights with a friend's help, accompanied him to Dignitas, arranged for Swiss carers, attended two suicide consultations between James and his Swiss doctor, and attended the Dignitas clinic on the day of the suicide.[34]

Despite the amount of support and assistance given by James' parents, the DPP decided not to prosecute them for assisted suicide. The DPP said, 'While there is sufficient evidence for a realistic prospect of conviction of [Daniel James' parents]…such a prosecution is not in the public interest'.[35] In December 2008, the DPP took the unprecedented step of publishing the reasons for his decision not to prosecute James' parents.[36] The DPP found that the guidance on whether or not to prosecute provided by the Code for Crown Prosecutors ('CCP')[37] was unsuitable for the offence of assisted suicide:

> I consider that the offence of aiding and abetting the suicide of another…is

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[29] See section 3.3.1.

[30] P Lewis, *Assisted dying and legal change* (OUP 2007) 24.

[31] Paralysis from the chest down. See *KMLE Medical Dictionary* <www.kmle.com/search.php?Search=tetraplegia> accessed 8 May 2014.

[32] CPS, Starmer, 'Decision on Prosecution — The Death by Suicide of Daniel James' (ch1 n25) paras 1 and 4.

[33] ibid para 8.

[34] ibid paras 12–15.

[35] ibid.

[36] ibid para 39. The factors that mitigated against prosecution were, i) the likelihood of both a serious penalty and of re-offence were small, ii) the offence was not pre-meditated nor were James' parents 'organisers' of a crime, iii) no pressure had been placed on James and no advantage was obtained, iv) the acts were more remote than 'direct' assistance in suicide, and v) prosecution was unlikely to boost 'community confidence'. ibid paras28– 36. The DPP observed that, although James' parents were in a position of trust, James was a mature, intelligent and fiercely independent young man, with full capacity to make decisions about his medical treatment, whose determination to commit suicide was not in any way influenced by the conduct or wishes of his parents. ibid paras30–32.

[37] CCP (ch1 n33) para4.12.

> unique in that the critical act—suicide—is not itself unlawful, unlike any other aiding and abetting offence. For that reason, I have decided that many of the factors identified in the [CCP] in favour or against a prosecution do not really apply in this case.[38]

It is submitted that the DPP's decision not to prosecute James' parents and his published reasons did little to make the position regarding prosecution clear for others who might wish to assist in a loved one's suicide.

The House of Lords in the subsequent case of *Purdy* (discussed below) noted that whilst the DPP's reasoning was 'generally helpful', it did not provide sufficient clarity as to how the CCP should be applied to cases of assisted suicide.[39] Lord Neuberger observed that there was no guarantee that the DPP's position would not change in the future, or that his reasoning in the Daniel James case would extend beyond the particular facts of that case.[40] The House of Lords accepted that the factors in the CCP were not applicable to the Daniel James case. As Baroness Hale held, '… the way in which the DPP had to explain his decision…shows that some of the listed factors have to be turned on their head and other unlisted factors introduced in order to cater for these difficult decisions'.[41] In the same way, Lord Hope held:

> The [DPP's] own analysis shows that, in a highly unusual and extremely sensitive case of this kind, the [CCP] offers almost no guidance at all. The question whether a prosecution is in the public interest can only be answered by bringing into account factors that are not mentioned there. Furthermore, the further factors that were taken into account in the case of Daniel James were designed to fit the facts of that case.[42]

The Daniel James case was influential in prompting the House of Lords in *Purdy* to request the DPP to create an offence-specific prosecution policy clarifying the public interest factors that would be taken into account for the offence of assisted suicide.

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[38] CPS, Starmer, 'Decision on Prosecution — The Death by Suicide of Daniel James' (ch1 n25) para39.

[39] *Purdy* (HL) (ch1 n31)[85].

[40] ibid [97].

[41] ibid [64].

[42] ibid [53].

– *Debbie Purdy*

Owing to progressive debilitating multiple sclerosis, Debbie Purdy was concerned that by the time she was ready to end her life by committing suicide, she would no longer be physically able to do so.[43] She anticipated that she would need to travel abroad to Dignitas for an assisted suicide but that she would, by that stage, only be capable of doing this with the help of her husband.[44] In December 2007, Purdy requested the DPP in writing to disclose his offence-specific prosecution policy on how he exercised his discretion to prosecute for assisted suicide, and if no such policy existed, to formulate one. The DPP replied in January 2008 stating, 'There is no such policy; and indeed…any such policy…would be unlawful'.[45] Purdy then applied to the High Court for a judicial review of the DPP's refusal to provide prosecuting guidelines for the offence of assisted suicide.

The issue before the High Court was 'whether the [DPP] ha[d] acted unlawfully in failing to publish detailed guidance [on] the circumstances in which individuals will ... be prosecuted for assisting another person to commit suicide'.[46] As had been argued in *Pretty*, Purdy argued that section 2(1) of the SA 1961 interfered with her right to private and family life under Article 8(1) of the ECHR.[47] According to her, in the absence of the clarity that an offence-specific prosecution policy would provide, such interference did not fall within the justifications permitted in Article 8(2)[48]. Purdy argued that Article 8(2) requires the law to be accessible, foreseeable and precise in order for individuals to know in advance whether their conduct will be unlawful.[49] As the High Court was bound by the House of Lords' decision in *Pretty* (discussed above), it held that Article 8(1) was not engaged.

On appeal, the House of Lords distinguished Purdy's case from *Pretty*.[50] Pretty had requested the DPP to grant her husband immunity from prosecution if he were to assist her to commit suicide at a later date. However, Purdy was requesting that the DPP publish an offence-specific prosecution policy detailing the factors that would be taken

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[43] *R (Purdy) v DPP* [2009] EWCA 92 [4]–[5],[9].

[44] ibid [6],[8].

[45] ibid [12].

[46] *R (Purdy) v DPP* [2008] EWHC 2565 [1] (Scott Baker LJ).

[47] *Purdy* (HL) (ch1 n31)[28].

[48] art 8(2) (n25).

[49] *Purdy* (HL) (ch1 n31)[28].

[50] ibid [30],[31].

into account by the DPP when deciding whether to prosecute. The House of Lords decided that it was free to depart from its earlier decision in *Pretty*, and to follow the ECtHR decision in *Pretty* that Article 8(1) was engaged, and that it extended to one's right to end their own life.[51]

The House of Lords held that when the law prevents an individual from exercising autonomous decisions that affect their quality of life,[52] this constitutes an interference with their right to private life.[53] This right to make autonomous choices regarding one's quality of life includes an autonomous decision to end life.[54] Baroness Hale held that, '[I]f the court is serious about protecting autonomy [then it must] accept that autonomous individuals have different views about what makes their lives worth living'.[55] Lord Brown accepted that there would be occasions where those assisting in suicide would have to be excused, to protect the victim's right to private life:

> [T]here will on occasion be situations where…it would be possible to regard the conduct of the aider and abettor as altruistic rather than criminal, conduct rather to be understood out of respect for an intending suicide's rights under [A]rticle 8 than discouraged so as to safeguard the right to life of others under [A]rticle 2.[56]

The House of Lords considered whether Article 8(2) provided scope for the DPP to interfere with one's right to end their own life with the assistance of another, by exercising his discretion to prosecute under section 2(4) of the SA 1961. Their Lordships found that the consequences of assisting a suicide were not sufficiently foreseeable under section 2(4), and that more guidance was required. Their Lordships were of the opinion that the generic CCP, which identifies factors which may bear upon the DPP's discretion to prosecute in a wide range of cases, did not satisfy the Article 8(2) requirements of 'accessibility' and 'foreseeability' for a person seeking to identify the factors likely to be taken into account by the DPP pursuant to section 2(4) of the SA 1961.[57]

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[51] ibid [34].

[52] See ch4.

[53] *Purdy* (HL) (ch1 n31)[39].

[54] NM Gorsuch, *The Future of Assisted Suicide and Euthanasia* (Princeton University Press, 2006) 96,98−99.

[55] *Purdy* (HL) (ch1 n31)[66]. See section 3.3.4 for 'respect for autonomy'.

[56] ibid [53].

[57] See Court of Appeal judgment in Nicklinson, Lamb and Martin's joint appeal: *Nicklinson* (CA) (ch1 n10) [119].

Their Lordships believed that this lack of clarity in the DPP's prosecution policy for assisted suicide meant that section 2(4) of the SA 1961 could not be justified under Article 8(2).[58] In July 2009, the House of Lords held that in order to satisfy Article 8(2), the DPP would need to promulgate an offence-specific policy; identifying the facts and circumstances which he will take into account in deciding whether or not to consent to a prosecution of an assisted suicide case such as Debbie Purdy's.[59]

Referring to the offence-specific prosecution policy which would be required, Lord Brown described it as:

> a custom-built policy statement indicating the various factors for and against prosecution,…factors designed to distinguish between those situations in which, however tempted to assist, the prospective aider and abettor should refrain from doing so, and those situations in which he or she may fairly hope to be, if not commended, at the very least forgiven, rather than condemned, for giving assistance.[60]

In that order, Lord Neuberger clarified that:

> the [DPP] ought to formulate…and publish a policy, which sets out what he would generally regard as the aggravating factors and mitigating factors, when deciding whether to sanction a prosecution under section 2 of the [SA] 1961…Inevitably, as a matter of common sense as well as a matter of law, each case will have to be decided by reference to its own particular facts, and the contents of such a policy could not conceivably be exhaustive.[61]

Baroness Hale stated that the DPP's offence-specific prosecution policy, should not only be based on one's right to autonomy, but also on making sure that one's decision to end life is not the result of pressure, coercion or duress:

> Clearly, the prime object must be to protect people who are vulnerable to all sorts of pressures …[and]… at the same time, the object must be to protect the right to exercise a genuinely autonomous choice. The factors which tell

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[58] M Beckford and R Prince, 'Debbie Purdy wins House of Lords victory to have assisted suicide law clarified' *The Telegraph* (London,31 July 2009).

[59] *Purdy* (HL) (ch1 n31)[56].

[60] ibid [86].

[61] ibid [101].

> for and against such a genuine exercise of autonomy free from pressure will be the most important.[62]

Baroness Hale's judgment also focused on the need for society, in certain situations, to value the lives of others who have given up on life. 'It is not for society to tell people what to value about their own lives, [however at times, it] may be justifiable for society to insist that we value their lives even if they do not'.[63] Baroness Hale noted in her judgment that:

> [I]n attitudinal surveys the British public have consistently supported assisted dying for people with a painful or unbearable incurable disease from which they will die, if they request it, while rejecting it for people with other reasons for wanting to die (National Centre for Social Research, *British Social Attitudes, The 23rd Report*, 2007, chapter 2).[64]

Thus, Baroness Hale was more in favour of a policy permitting assisted death to those who are suffering unbearably from a terminal illness.

Seven months after the House of Lords' judgment in *Purdy*, the DPP published an offence-specific prosecuting policy for the offence of assisted suicide. This prosecuting policy will be examined in section 2.2.3 below.

– *Tony Nicklinson*

Tony Nicklinson's case went further than the earlier assisted suicide cases discussed above. Nicklinson had suffered a stroke in June 2005, leaving him almost completely paralysed with 'locked-in' syndrome.[65] As a consequence, he could only communicate by blinking. Although Nicklinson's condition was not life-threatening, in 2007 he decided to end his life. He was not physically able to take his own life, and was prohibited by law from obtaining the assistance of a doctor.[66] Thus, Nicklinson sought a court declaration that the common law defence of necessity would be available to anyone who assisted him to die. As discussed in Chapter One,[67] the High Court ruled

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[62] *Purdy* (HL) (ch1 n31)[65]. See section 3.4.6 for 'protecting the vulnerable'.

[63] ibid [66].

[64] ibid [66].

[65] *Nicklinson* (CA) (ch1 n10)[11].

[66] ibid [11].

[67] See section 1.1.1 in ch1.

against his application. Nicklinson died in August 2012, a week after the High Court ruling. He had refused nutrition, fluids, and medical treatment prior to his death.[68]

Nicklinson's wife then appealed to the Court of Appeal on Nicklinson's behalf. She sought to establish a right to die with dignity[69] at a time of one's own choosing. Mrs Nicklinson's appeal relied on fundamental common law rights.[70] She argued that the common law should provide a defence to murder where the crime takes the form of 'euthanasia'.[71] The Court, however, rejected the argument that the common law should recognise a defence of necessity in cases of euthanasia, for the following four reasons.[72]

First, the Court of Appeal held that the rights of autonomy[73] and dignity have to yield to the sanctity of life[74] which is a fundamental principle of the common law, reflected in the unqualified right to life found in Article 2 of the ECHR.[75] Second, the Court held that section 1 of the SA 1961 should be regarded as conferring immunity from the criminal process for those who actually commit suicide rather than as conferring one with a right to commit suicide. As such:

> if there is no right to kill yourself, there can be no right, fundamental or otherwise, to require the State to allow others to assist you to die or to kill you. That analysis cannot be altered by the simple expedient of recasting what is at best a liberty or freedom to commit suicide as the exercise of a positive right to autonomy and dignity.[76]

Third, the Court held that it was inappropriate for the Court to fashion a defence of necessity in a complex and controversial issue like euthanasia, but that this was a matter for Parliament.[77] The court stated that:

> Parliament as the conscience of the nation is the appropriate constitutional forum, not judges who might be influenced by their own particular moral

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[68] *Nicklinson* (CA) (ch1 n10)[12].

[69] See section 3.4.4.

[70] *Nicklinson* (CA) (ch1 n10)[16].

[71] ibid [38].

[72] ibid [54].

[73] See section 3.3.4.

[74] See section 3.3.1.

[75] *Nicklinson* (CA) (ch1 n10)[54].

[76] ibid [55].

[77] ibid [56].

> perspectives; the judicial process which has to focus on the particular facts and circumstances before the court is not one which is suited to enabling the judges to deal competently with the range of conflicting considerations and procedural requirements which a proper regulation of the field may require; and there is a danger that any particular judicial decision, influenced perhaps by particular sympathy for an individual claimant, may have unforeseen consequences, creating an unfortunate precedent binding in other contexts.[78]

Fourthly, the Court held that:

> any defence provided to those who assist someone to die would have to apply not merely to euthanasia but also to assisted suicide. That immediately raises the question: how can the courts develop a defence to assisted suicide when Parliament has stated in unequivocal terms that it is a serious criminal offence carrying a maximum sentence of 14 years' imprisonment.[79]

In her appeal to the Court of Appeal, Mrs Nicklinson also relied on the right to private life under Article 8 of the ECHR.[80] She argued that the legal prohibition on assisted death constituted a disproportionate interference with one's right under Article 8.[81] This issue on whether the interference with the Article 8(1) right meets the criteria for permissible interference laid down in Article 8(2)[82] was dealt with extensively in the cases of *Pretty* and *Purdy* (discussed above).[83] Thus, the Court of Appeal referred to these earlier judgments and held that the blanket prohibitions on euthanasia and assisted suicide do not constitute a disproportionate interference with one's rights under Article 8.[84] Mrs Nicklinson's appeal was accordingly dismissed in July 2013. Her appeal was joined by two other individuals (Paul Lamb and 'Martin') suffering from permanent physical disabilities. The Court of Appeal's ruling on the submission made by the individual known as 'Martin', concerning the likelihood of healthcare professionals being prosecuted, will be dealt with under *Healthcare professionals* in section 2.2.3, which follows.

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[78] ibid [60].

[79] ibid [64].

[80] ibid [16].

[81] ibid [40].

[82] art 8(2) (n25).

[83] *Nicklinson* (CA) (ch1 n10)[34].

[84] ibid [114].

2.2.3 *Interim Policy and DPP's Policy*

In September 2009, less than two months after the House of Lords' judgment in *Purdy*,[85] the DPP published a draft offence-specific prosecuting policy for the offence of assisted suicide. This policy, the *Interim Policy for Prosecutors in Respect of Cases of Assisted Suicide* ('Interim Policy'), set out public interest factors that were to be taken into account by the DPP for assisted suicide cases.[86] At the same time, a public consultation exercise, which received nearly 5,000 responses, was initiated by the Crown Prosecution Service (CPS).[87] Following the public consultation, the *Policy for Prosecutors in Respect of Cases of Encouraging or Assisting Suicide* ('DPP's Policy') was published in February 2010.[88] The DPP's Policy sets out 22 public interest factors — 16 in favour of prosecution and six against prosecution. The 22 public interest factors listed within the DPP's Policy are laid out in Table 1, overleaf.

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[85] *Purdy* (HL)(ch1 n31)[56].

[86] Crown Prosecution Service (CPS), *Interim Policy for Prosecutors in Respect of Cases of Assisted Suicide* (2009) ('DPP's Interim Policy') <www.cps.gov.uk/consultations/as_policy.html> accessed 19 June 2014.

[87] CPS, 'Public Consultation Exercise on the Interim Policy for Prosecutors in respect of Cases of Assisted Suicide Issued by the Director of Public Prosecutions, Summary of Responses' (February 2010) 39 <www.cps.gov.uk/consultations/as_responses.html> accessed 19 June 2014.

[88] DPP's Policy (ch1 n34).

Factors tending in favour of prosecution (numbered as per DPP’s Policy, para 43)	**Factors tending against prosecution** (numbered as per DPP’s Policy, para 45)
The victim: (1) was under 18 years of age; (2) did not have the capacity (as defined by the Mental Capacity Act 2005) to reach an informed decision to commit suicide; (3) had not reached a voluntary, clear, settled and informed decision to commit suicide; (4) had not clearly and unequivocally communicated his or her decision to commit suicide to the suspect; (5) did not seek the encouragement or assistance of the suspect personally or on his or her own initiative; (10) was physically able to undertake the act that constituted the assistance him or herself;	The victim: (1) had reached a voluntary, clear, settled and informed decision to commit suicide;
The suspect: (6) was not wholly motivated by compassion; for example, the suspect was motivated by the prospect that he or she or a person closely connected to him or her stood to gain in some way from the death of the victim; (7) pressured the victim to commit suicide; (8) did not take reasonable steps to ensure that any other person had not pressured the victim to commit suicide; (9) had a history of violence or abuse against the victim; (11) was unknown to the victim and encouraged or assisted the victim to commit or attempt to commit suicide by providing specific information via, for example, a website or publication; (12) gave encouragement or assistance to more than one victim who were not known to each other; (13) was paid by the victim or those close to the victim for his or her encouragement or assistance; (14) was acting in his or her capacity as a medical doctor, nurse, other healthcare professional, a professional carer [whether for payment or not], or as a person in authority, such as a prison officer, and the victim was in his or her care; (15) was aware that the victim intended to commit suicide in a public place where it was reasonable to think that members of the public may be present; (16) was acting in his or her capacity as a person involved in the management or as an employee (whether for payment or not) of an organisation or group, a purpose of which is to provide a physical environment (whether for payment or not) in which to allow another to commit suicide.	The suspect: (2) was wholly motivated by compassion; (4) had sought to dissuade the victim from taking the course of action which resulted in his or her suicide; (6) reported the victim’s suicide to the police and fully assisted them in their enquiries into the circumstances of the suicide or the attempt and his or her part in providing encouragement or assistance. The actions of the suspect: (3) although sufficient to come within the definition of the offence, were of only minor encouragement or assistance; (5) may be characterised as reluctant encouragement or assistance in the face of a determined wish on the part of the victim to commit suicide;

Table 1 Public interest factors listed within the DPP’s Policy

Concerns raised during the public consultation, along with issues relating to the DPP's Policy will be considered below.

– *Suspect's motivation*

Factor 7 in favour of prosecution in the Interim Policy focused on suspects who were not wholly motivated by compassion, but who were motivated by the prospect that they or a person closely connected to them stood to gain in some way from the victim's death.[89] Respondents to the public consultation stated that there may be practical difficulties with the phrase 'stood to gain', as there will be many instances where some gain is secured by the suspect as a result of the victim's death.[90] It is contended here that there are difficulties in establishing the true motives behind an assisted suicide in circumstances where the person assisting may have acted out of mixed motives, i.e. partly by compassion but also in part by a desire to put an end to a difficult family situation or to gain some material benefit from the patient's death.[91]

A new public interest factor against prosecution – that the suspect did not stand to gain any advantage, financial or otherwise, from the death of the victim – was identified in the consultation exercise.[92] Its underlying principle is now covered by Factor 6 in the DPP's Policy in favour of a prosecution, which states that: '[t]he suspect was not wholly motivated by compassion; for example, the suspect was motivated by the prospect that he or she or a person closely connected to him or her stood to gain in some way from the death of the victim.'[93]

To put 'stood to gain' in context, the DPP's Policy states:

> On the question of whether a person stood to gain, ... the police and ... prosecutor should adopt a common sense approach. It is possible that the suspect may gain some benefit – financial or otherwise – from the resultant suicide of the victim after his or her act of encouragement or assistance. The critical element is the motive behind the suspect's act. If it is shown that

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[89] 'Public Consultation Exercise on the Interim Policy for Prosecutors' (n87)[2.14].

[90] ibid [2.14].

[91] Otlowski (ch1 n88).

[92] 'Public Consultation Exercise on the Interim Policy for Prosecutors' (n87)[7.4].

[93] DPP's Policy (ch1 n34) para43(6).

> compassion was the only driving force behind his or her actions, the fact that the suspect may have gained some benefit will not usually be treated as a factor tending in favour of prosecution…each case must be considered on its own merits and…facts.[94]

This is demonstrated in the case of Sir Edward Downes and his wife, Lady Edwina Downes, who were both accompanied by their son to Dignitas, where they ended their lives. The DPP decided that there was no evidence that the son was motivated by the financial gain he received upon their deaths.[95] The DPP said, '[t]he evidence and information available indicate[d] that [he] was wholly motivated by compassion'.[96]

It has been contended that the DPP's Policy represents 'an excusatory as opposed to a justificatory approach',[97] where 'the granting of [an] excuse is in part linked to the experience of conscience-driven emotional pressures arising from [the suspect's] special relationship with [the victim]'.[98] It is submitted that the introduction of a 'compassionate' motive in the DPP's Policy is a departure from the usual standards of criminal law.[99] The classic elements of a crime are the *actus reus* and *mens rea*, with motive being irrelevant.[100] Nevertheless, a 'compassionate' motive has been a consideration against prosecution for assisted suicide, even prior to the DPP's Policy being published.[101] For example, it had influenced the DPP's decision to not prosecute the parents of Daniel James (discussed above).[102] It is contended that there are practical difficulties in investigating a suspect's motives following a victim's death.[103] The DPP's Policy involves a retrospective assessment of a suspect's motives, after the death of the victim, whereas the victim in such cases may have been the only person able to bear witness to the suspect's motives in any meaningful sense.[104]

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[94] ibid para44.

[95] 'No assisted suicide charge for son of Sir Edward Downes' (*BBC News*,19 March 2010).

[96] CPS, 'Statement by Keir Starmer QC regarding the deaths of Sir Edward and Lady Downes' (19 March 2010), <www.cps.gov.uk/news/latest_news/the_death_of_sir_edward_and_lady_downes/ > accessed 19 June 2014.

[97] P Lewis, 'Informal legal change on assisted suicide: the policy for prosecutors' (2011)31(1) LS 119,129.

[98] J Horder, *Excusing Crime* (OUP 2007)228.

[99] HM Biggs, 'Legitimate Compassion or Compassionate Legitimation? Reflections on the Policy for Prosecutors in Respect of Cases of Encouraging or Assisting Suicide' (2011)19 Feminist LS 83,87.

[100] ibid 90.

[101] ibid 86.

[102] ibid 86.

[103] A Mullock, 'Overlooking the Criminally Compassionate: What Are the Implications of Prosecutorial Policy on Encouraging or Assisting Suicide?' (2010)18 Med.L.Rev 442,453.

[104] ibid.

– *Victim's mental capacity*

The Interim Policy considered the victim's 'mental capacity' and included factors that required the victim to have reached a clear, settled and informed wish to commit suicide. This was reflected in Factor 3 in favour of prosecution, and Factor 1 against prosecution, in the Interim Policy.[105] This was a recognition of a victim's competent autonomous decision to end their life. However, only 38% of respondents to the public consultation supported the inclusion of these factors.[106] The CPS was, nevertheless, of the view that the absence of a victim's informed and settled decision to commit suicide should be a factor in favour of prosecution.[107] Thus, the second factor in favour of prosecution in the DPP's Policy provides for situations where the victim did not have the capacity, as defined by the Mental Capacity Act 2005 ('MCA 2005'),[108] to reach an informed decision to commit suicide.[109]

It is, however, argued that the definition of a person who lacks capacity in the MCA 2005 is unclear. The group of persons falling within this definition may be wide, as the MCA 2005 does not provide any examples or illustrations.[110] Section 2 of the MCA 2005 provides that a person lacks capacity if they are unable to make a decision because of an impairment or disturbance in the functioning of the mind or brain, whilst section 3 provides that a person would be unable to make a decision when they are unable to i) understand the information relevant to the decision, ii) retain the information, iii) use or weigh the information as part of the process of making that decision, or iv) communicate that decision. Additionally, as the MCA 2005 does not require a psychological or psychiatric assessment for determining capacity, clinical depression or any other mental disorders impairing a person's decision-making capacity may be undetected under the Act.

Furthermore, criminal investigations for assisted suicide take place after a victim has died, when investigators must rely on retrospective, second-hand accounts to establish a victim's competence, and motivation for choosing to end their life.[111] As such, reliance

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[105] DPP's Interim Policy (n86).

[106] 'Public Consultation Exercise on the Interim Policy for Prosecutors' (n87)[6.10].

[107] ibid [6.11].

[108] The MCA 2005 provides a statutory framework for treating adults who are unable to consent to treatment. See section 2.3.3 under *Advance decisions* and *Best interests*.

[109] DPP's Policy (ch1 n34) para43(2).

[110] Cohen (ch1 n30).

[111] APPG, 'Bill consultation: Latest news' (ch1 n56).

on the DPP's Policy after the fact, fails to adequately protect the interests of those who may be vulnerable[112] to abuse, coercion, pressure or exploitation.[113]

– *Suspect's assistance*

The DPP's Policy fails to provide any guidance as to what actions amount to 'minor encouragement or assistance' as described in the third public interest factor tending against prosecution.[114] Lewis argues that direct acts of assistance such as providing medication, writing a prescription, setting up an intravenous drip which is then triggered by the patient, crushing or dissolving medication or other technical or practical assistance with the act of suicide itself will make prosecution more likely than less proximate assistance, such as making travel arrangements to a right-to-die organisation abroad.[115] In the case of Sir Edward Downes and Lady Edwina Downes, the DPP decided that the son's actions in booking a hotel room in Switzerland for his parents, and in accompanying them there, where they subsequently committed suicide at Dignitas, 'although sufficient to come within the definition of the offence, were very much only of minor assistance'.[116] It is argued that the DPP's Policy lacks clarity in relation to this factor. The DPP's Policy does not provide any specific examples, circumstances, or illustrations of what would make a suspect's acts of assistance more or less likely to be prosecuted.[117]

The DPP stated in both the Interim Policy[118] and the DPP's Policy,[119] that each case is to be judged on its own facts and merits. He said:

> Prosecutors must decide the importance of each public interest factor in the circumstances of each case and go on to make an overall assessment. It is quite possible that one factor alone may outweigh a number of other factors which tend in the opposite direction.[120]

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[112] See section 3.4.6.

[113] Biggs (n99) 90.

[114] DPP's Policy (ch1 n34) para45(3).

[115] Lewis (n97) 121.

[116] 'Statement by Keir Starmer QC regarding the deaths of Sir Edward and Lady Downes' (n96).

[117] Mullock (n103) 451.

[118] DPP's Interim Policy (n 86)[15],[16].

[119] DPP's Policy (ch1 n34) paras39-40.

[120] ibid para39.

This is illustrated in the 2010 case of Michael Bateman. Bateman assisted his wife's suicide by assembling a helium gas apparatus and placing a plastic bag over her head, before his wife herself turned on the helium supply and tightened the bag.[121] Although Bateman's actions could hardly be described as constituting 'only minor assistance or encouragement', the DPP concluded that Bateman had been wholly motivated by compassion and that it was not in the public interest to prosecute him.[122] In this case, Bateman's compassionate motive amounted to an overriding public-interest factor against prosecution. It is thus submitted that, allowing the DPP's Policy to place a criminal act beyond the reach of the criminal courts on the basis of a 'compassionate' motive whilst assisted suicide remains a crime is incoherent.

– *Victim's physical or medical condition*

Factor 6 in favour of prosecution in the Interim Policy[123] – that the victim did not have a terminal illness, a severe and incurable physical disability, or a severe degenerative physical condition, from which there was no possibility of recovery – and Factor 4 against prosecution in the Interim Policy[124] – that the victim had a terminal illness, or a severe and incurable physical disability, or a severe degenerative physical condition, from which there was no possibility of recovery – received the most feedback during the public consultation. An estimated 1,200 respondents specifically asked the CPS to reconsider the inclusion of these factors, on the basis that they could be seen as discriminatory against those with a serious illness or disability.[125] Accepting that it was inappropriate for any factor to suggest that a relevant act was somehow less serious simply by virtue of the victim's physical condition, the CPS removed these factors from the DPP's Policy.[126]

Gorsuch also cogently argues that a prosecution policy which purports to respect autonomy[127] should exclude any qualifying factors regarding an individual's physical

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[121] CPS, 'Assisted Suicide Charge Not in the Public Interest'(24 May 2010) <www.cps.gov.uk/news/latest_news/120_10/> accessed 19 June 2014, noting that Michael Bateman's wife had been bedridden for years due to an undiagnosed condition.

[122] M Moore , 'Man who helped wife commit suicide will not be prosecuted' *The Telegraph* (London, 25 May 2010).

[123] 'Public Consultation Exercise on the Interim Policy for Prosecutors' (n87)[2.10].

[124] ibid [6.14].

[125] ibid [6.15].

[126] ibid [6.17].

[127] See section 3.3.4.

condition. He asserts that to fully comply with the principles of autonomy, a State must 'abstain from coercively interfering with any rational adult's private decision to die, whatever the motive or reason for the individual's considered decision'.[128] It is, however, argued that by disregarding a victim's physical condition, it may not be practical for prosecutors to decide if the suspect was compassionately motivated to assist in the victim's suicide.[129] An objective assessment of whether a suspect's assistance was motivated by compassion will naturally involve an assessment of whether the victim was suffering.[130] Thus, an assessment of a victim's physical condition is unavoidable. The benefit of referring to a patient's physical condition is supported by Factor 10 in favour of prosecution in the DPP's Policy, which states that a prosecution is more likely if 'the victim was physically able to undertake the act that constituted the assistance him or herself.'[131]

As noted in Baroness Hale's judgment in *Purdy* (discussed above), a large majority of the UK public support the legalisation of assisted death for the terminally ill.[132] This support was also evidenced in the DPP's public consultation. Respondents had proposed that if there is written documentation outlining a victim's request and intentions to commit suicide (e.g. a Living Will), and if a doctor had confirmed that the victim was terminally ill, then these should be factors against prosecution.[133] Baroness Hale's judgment in *Purdy* also highlighted that there is less support amongst the British public for assisted death to be allowed for people with reasons other than a painful or unbearable incurable disease from which they will die.[134] Support for this is demonstrated in a 2010 poll by ComRes for the BBC's current affairs programme, 'Panorama'.[135] The poll found that 74% of respondents supported physician-assisted suicide for the terminally ill, while 73% were in favour of a family member or close friend assisting the suicide of a terminally ill person. However, only 45% were in favour of physician-assisted suicide for non-terminally ill patients with a painful and incurable condition, and 48% were in favour of a family member or close friend assisting the suicide of a non-terminally ill person. Nevertheless, the DPP maintained, in his public

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[128] Gorsuch (n54) 98−99.

[129] Mullock (n103) 462.

[130] ibid 463.

[131] DPP's Policy (ch1 n34) para43(10).

[132] *Purdy* (ch1 n31)[66].

[133] 'Public Consultation Exercise on the Interim Policy for Prosecutors' (n87)[7.3].

[134] *Purdy* (ch1 n31)[66].

[135] 'Assisted Suicide Survey: CATI Fieldwork: January 8th-10th 2010', prepared for BBC Panorama (ComRes).

consultation exercise, that only Parliament can set out the criteria or requirements that might be appropriate for an exemption from prosecution for the offence of assisted suicide.[136]

In this thesis, it is argued that the reform of the law on assisted suicide should be limited to terminally ill patients only. The results of different opinion polls show support for such a restriction on eligibility. In the 2005,[137] 2007[138] and 2010[139] *BSA* surveys, 80% of respondents thought that assisted death should be allowed for terminally ill patients, while only 45% thought it should be available to people with incurable but non-terminal illness. Other public opinion surveys delivered similar results. A Populus poll for *The Times* newspaper in July 2009 found that among the 85% of respondents who supported assisted suicide in 'specific circumstances', 95% thought that assisted suicide should be legal for people who are terminally ill.[140]

– *Healthcare professionals*

Factor 14 of the public interest factors in favour of prosecution in the Interim Policy provides that, 'The suspect was paid to care for the victim in a care/nursing home environment'.[141] Respondents to the public consultation commented that it was inappropriate to single out professional carers working in particular environments.[142] An estimated 34% of comments suggested that it should be a factor in favour of prosecution if the suspect was a nurse, doctor or other healthcare professional and the victim was in their care.[143] In response, the CPS amended Factor 14, which now reads:

> the suspect was acting in his or her capacity as a medical doctor, nurse, other healthcare professional, a professional carer [whether for payment or not], or as a person in authority, such as a prison officer, and the victim was in his or her care.[144]

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[136] 'Public Consultation Exercise on the Interim Policy for Prosecutors' (n87)[7.6].

[137] Park and Clery (ch1 n60).

[138] Clery (ch1 n61).

[139] McAndrew (ch1 n70).

[140] 'The Times Poll: July 17th-19th 2009' (ch1 n62).

[141] DPP's Interim Policy (n86).

[142] 'Public Consultation Exercise on the Interim Policy for Prosecutors' (n87)[3.6]-[3.7].

[143] ibid [3.3].

[144] DPP's Policy (ch1 n34) para43(14).

It is submitted that a key driver for this amended Factor 14 is the potential conflict between assisting a suicide and a physician's traditional role and responsibilities towards a patient.[145] By specifically deterring healthcare professionals from providing suicide assistance, Factor 14 (as amended) now places a heavier burden on the friends and family of a victim. An unintended consequence of this may be an increase in failed suicides, assisted by well-meaning, but ill-trained loved ones.[146]

The DPP's Policy deters physicians from justifying any current conduct of assisting suicides.[147] By contrast, in the Netherlands (discussed in Chapter Five), physicians are permitted to rely on a defence of necessity, when assisting the deaths of patients who are experiencing intolerable pain and suffering that cannot be alleviated. The DPP's Policy could have similarly reduced the incidence of unregulated medical killing. A study by Seale on end-of-life medical decisions in the UK between 2007 and 2008[148] found that patients were already being assisted to die by physicians. The survey found that approximately 0.5% of all deaths in the UK are as a result of euthanasia. 0.2% of all deaths constituted voluntary euthanasia, where 'following a request from a patient, a drug is administered with the explicit intention of ending life', whilst 0.3% of all deaths were identified as 'ending life without an explicit request from patient' (or non-voluntary euthanasia[149]). This constitutes approximately 2,500 unlawful deaths (of the 500,000 total deaths per year) facilitated by healthcare professionals without any appropriate safeguards or transparency on their 'unlawful' end-of-life medical practice.[150]

The thesis argues that society's needs would be better served if healthcare professionals were not explicitly discouraged from assisting suicides under the DPP's Policy. Healthcare professionals have the expertise necessary to achieve a safe and humane assisted death, and are the main gatekeepers of the medications needed to reliably and humanely achieve this.[151] They are also better able than members of the general public to

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[145] Discussed in text to nn375-378.

[146] For example, a terminally ill man, William Stanton, recently survived a suicide pact in which his wife, who was healthy, died. See 'Terminally ill doctor survived suicide pact which killed wife because bag used to suffocate himself was too small' *Daily Mail* London,19 August 2010).

[147] Lewis (n97) 129.

[148] C Seale, 'End-of-life decisions in the UK involving medical practitioners' (2009)23 Palliative Medicine 198.

[149] 'Non-voluntary euthanasia' (text to ch1 n98).

[150] APPG, 'Bill consultation: Latest news' (ch1 n56).

[151] P Lewis, 'Comment: What has 'Martin' won?' (KCL Medical Ethics and Law: A blog by the Centre of Medical Law and Ethics, King's College London, 31 July 2013) <http://kclmedicalethicsandlaw.wordpress.com> accessed 1 August 2013.

detect whether a patient's decision to die is impaired by depression or some other psychiatric or psychological disorder. The involvement of healthcare professionals would consequently give greater certainty of outcome, lower the risk of botched suicides[152] and of suffering during the suicide.[153]

The results of public opinion surveys in the UK show that there is more support for physician-assisted suicide, than for relatives or friends to be permitted to assist in suicides. The 2005 *BSA* survey found 60% of its respondents in favour of a law permitting physician-assisted suicide for terminally ill patients, whereas only 44% thought that relatives should be allowed to undertake this role.[154] More recent surveys have found strong support for both physician-assisted suicide and assisted suicide by friends and relatives. The July 2009 Populus poll, as referred to above, found that 74% of respondents were in favour of legalising physician-assisted suicide, and that 60% supported the legalisation of non-physician assisted suicide (i.e. by friends and relatives).[155] Similarly, a 2010 poll by ComRes found that 74% of its respondents supported physician-assisted suicide for the terminally ill, whilst 73% supported the idea of allowing family members or close friends to assist with suicides for the terminally ill.[156] It is submitted that the growing support by the public for family members and friends to assist with suicides may be due to the fact that physicians are not only legally prohibited but also disallowed by the medical professional bodies in England and Wales from taking active measures to end the lives of their patients.[157]

It is argued that the DPP's Policy is not clear on what might be legally permissible in terms of 'assistance' provided by healthcare professionals in assisted suicides. It is doubtful whether the DPP will apply his policy to a healthcare professional who merely provides a patient with their medical records in order for them to seek an assisted suicide abroad.[158] It would be a breach of Article 8 of the Human Rights Act 1998 for a

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[152] Gilderdale (ch1 n38).

[153] Biggs (n99) 88.

[154] Park and Clery (ch1 n60).

[155] 'The Times Poll: July 17th-19th 2009' (ch1 n62).

[156] 'Assisted Suicide Survey: CATI Fieldwork: January 8th-10th 2010' (n135).

[157] See section 3.3.3 for the views of the General Medical Council and British Medical Association on physician-assisted death.

[158] Lewis (n97) 121. Right-to-die organisations abroad require a patient's medical records to assess and evaluate them for assisted suicides. R Huxtable, 'The Suicide Tourist Trap: Compromise Across Boundaries' (2009)6 Bioethical Enquiry 327.

physician to refuse a patient their medical records.[159] Further, section 7 of the Data Protection Act 1998 provides a patient with a right of access to their medical records, provided the disclosure of such data does not cause 'serious harm' to the physical or mental health of the patient.[160] The 'serious harm' exception in section 7 is difficult to reconcile with patients who regard assisted suicide to be in their best interests.[161]

The lack of clarity in the DPP's Policy on 'permissible assistance' by healthcare professionals was considered by the Court of Appeal in *Nicklinson* (discussed above). Martin, who was joined as a party in Mrs Nicklinson's appeal, argued that the DPP's Policy fails to provide sufficient clarity on the assistance which is permissible by healthcare professionals or professional carers (whether for payment or not) to those requesting assisted suicide. Martin asserted that the DPP's Policy is an unjustified interference with his rights under Article 8 of the ECHR, as the interference is too uncertain to be 'in accordance with the law' as required by Article 8(2).[162] The Court of Appeal held that the phrase 'in accordance with law' requires the law to be clear, accessible and foreseeable.[163] The Court held that a person should be able to reasonably foresee the effect of their involvement or participation in someone's suicide, and that it is impossible to predict with certainty under the DPP's Policy whether a healthcare professional who assists a victim to commit suicide will be prosecuted or not.[164] The Court of Appeal judgment states:

> Despite the wording of the order made in *Purdy*, we consider that it is not sufficient for the [DPP's] Policy merely to list the factors that the DPP will take into account in deciding whether to consent to a prosecution under section 2(1) [of the SA 1961]. A list of factors which contains no clue as to how the discretion to grant or withhold consent will be exercised is not sufficient to meet the requirements of Article 8(2)… If a list of relevant factors does not enable the person concerned to foresee, to a degree that is reasonable and adequate in the circumstances, the consequences of his action, then the Article 8(2) requirement is not satisfied. It is clear,

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[159] Huxtable (ibid) notes that as guardians of their patients' medical records, physicians are expected to release these documents to their patients.

[160] Data Protection (Subject Access Modification) (Health) Order 2000.

[161] Mullock (n103) 467.

[162] *Nicklinson* (CA) (ch1 n10)[114]. Article 8(2) is provided in n25.

[163] ibid [43].

[164] ibid [44].

> therefore, that the order made by the House of Lords in *Purdy* required the DPP to identify the facts and circumstances which he would take into account in such a way that a person who is considering providing assistance to a victim to commit suicide is able to foresee, to a degree that is reasonable and adequate in the circumstances, the consequences of providing such assistance.[165]

By a majority decision, the Court of Appeal in *Nicklinson* requested the DPP to amend the DPP's Policy to provide more clarity for healthcare professionals.[166] The Court of Appeal judgment states:

> In our judgment, the…[DPP's] Policy is in certain respects not sufficiently clear to satisfy the requirements of Article 8(2) in relation to healthcare professionals. It is not surprising that…[healthcare professionals] are reluctant to assist victims to commit suicide ... How does…[the DPP's Policy] apply in the case of a medical doctor or nurse who is caring for a patient and out of compassion is willing to assist the patient to commit suicide, but is not, as it were, in the business of assisting individuals to commit suicide and perhaps has never done so before? How much weight is given by the DPP to…[Factor 14 in favour of prosecution] alone? And if the professional accepts some payment for undertaking the task, will that be likely to involve a finding that he or she is not wholly motivated by compassion, thereby triggering both…[Factor 6 in favour of prosecution] … and…[Factor 13 in favour of prosecution] ? These questions are of crucial importance to healthcare professionals who may be contemplating providing assistance. It is of no less importance to victims who wish to commit suicide, but have no relative or close friend who is willing and able to help them to do so ... the…[DPP's] Policy should give some indication of the weight that the DPP accords to the fact that the helper was acting in his or

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[165] ibid [138].

[166] '[W]e accept that it would be impractical, if not impossible, for the DPP to lay down guidelines which would … enable every doctor or other professional to be able to tell as a matter of probability whether he or she would be prosecuted in a particular case. But it is not impossible or impractical to amend the Policy so as to make its application … more foreseeable than it currently is.': ibid [144]. The case was appealed to the Supreme Court. See O Bowcott, 'Right-to-die claims to be heard in supreme court, Lawyers for right-to-die campaigners will argue medical staff should be able to help those physically unable to end their lives' *The Guardian* (London,17 December 2013). The hearing took place the week of 16 December 2013 (UKSC 2013/0235). As at 1 January 2014, the case is awaiting judgment. <www.supremecourt.gov.uk/current-cases/CCCaseDetails/case_2013_0235.html> accessed 23 December 2013.

> her capacity as a healthcare professional and the victim was in his or her care…the Policy does not provide medical doctors and other professionals with the kind of steer…that it provides to relatives and close friends acting out of compassion.[167]

The fact that to date, no physicians have been prosecuted, in any capacity, for assisting a suicide abroad adds to the uncertainty in respect of 'permissible assistance' by healthcare professionals.[168] An example is the case of Dr Michael Irwin, though it must be appreciated that this case is of limited significance in the present context. The case occurred at a time when there was no offence-specific prosecuting policy for the offence of assisted suicide, and thus the DPP applied the public interest factors in the CCP.[169] In February 2007, Irwin assisted in the arrangements for Raymond Cutkelvin's suicide at Dignitas. This included visiting Cutkelvin to discuss the Dignitas procedures, contributing towards the Dignitas costs by paying £1,500 of his own money, and accompanying Cutkelvin on the flight to Switzerland.[170] These arrangements could be regarded as more than 'minor assistance',[171] yet the DPP stated that a prosecution would not be in the public interest, and Dr Irwin was not prosecuted.[172]

Although public opinion supports a change in the law to allow healthcare professionals to assist suicides, recent studies by Seale[173] and Lee et al[174] suggest that a majority of doctors are opposed to such a change. Both studies found that only between one-third and two-fifths of doctors are in favour of a more permissive approach to assisted suicide for those patients suffering from a terminal illness. Seale's 2007–2008 study of 3,733 doctors found that 35.2% of the doctors surveyed were in favour of physician-assisted

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[167] *Nicklinson* (CA) (ch1 n10) [140]. For Factor 14 in favour of prosecution, see DPP's Policy (ch1 n34) para 43(14) and text to n144. For Factor 6 in favour of prosecution, see DPP's Policy para 43(6) and text to n93. For Factor 13 in favour of prosecution, see DPP's Policy para 43(13). This public interest factor tending in favour of prosecution provides that, 'the suspect was paid by the victim or those close to the victim for his or her encouragement or assistance'.

[168] Mullock (n103) 467.

[169] CCP (ch1 n33).

[170] 'No charges following death of Raymond Cutkelvin' (*CPS*, 25 June 2010) <http://cps.gov.uk/news/latest_news/123_10> accessed 10 April 2013.

[171] DPP's Policy (ch1 n34) para 45(3).

[172] 'Euthanasia Doctor is Struck Off' (*BBC News*,27 September 2005), <http://news.bbc.co.uk/2/hi/health/4286470.stm> accessed 16 July 2013.

[173] C Seale, 'Legalisation of euthanasia or physician-assisted suicide: survey of doctors' attitudes' (2009)23(3) Palliative Medicine 205.

[174] W Lee et al, 'Survey of doctors' opinions of the legalisation of physician assisted suicide' (2009)10(2) BMC Medical Ethics 2.

suicide for the terminally ill, whilst only 21.7% were in favour for the chronically ill.[175] Lee et al's 2007 study was based on a sample of 372 questionnaires returned by doctors.[176] The study found that 39% of respondents supported a change in the law to permit assisted suicide for terminally ill patients and 49% were opposed to such a change. Of the 39% in support, only 31% were willing to personally facilitate physician-assisted suicide. Lee et al's survey further found that doctors who regularly worked with the dying were less likely to support a change in the law to permit physician assisted suicide. 66% of those never caring for the dying supported a change in the law, whilst 72% of those caring for the dying on a daily basis opposed it.

– *Previous suicide attempts*

Before the Interim Policy was introduced, a victim's previous suicide attempts were taken into account by the DPP when deciding whether to prosecute a suspect for assisted suicide. This is demonstrated in the case of Daniel James, where previous suicide attempts of the 23-year-old James were a factor against prosecuting his parents.[177] Despite this, Factor 11 against prosecution in the Interim Policy – that the victim had previously attempted to commit suicide and was likely to try to do so again – attracted substantial critical comment during the public consultation. Rather than regarding this as evidence of a voluntary, clear, settled and informed intent by a victim to end their life, an estimated 1,000 respondents fittingly considered a victim's previous suicide attempts as being equally indicative of their suffering from serious mental or physical issues.[178] They soundly argued that previous suicide attempts could be seen as a victim's 'cry for help', and that such vulnerable individuals could more properly benefit from increased care, or support, rather than being assisted to end their life.[179] As a result, Factor 11 was appropriately removed from the DPP's Policy.

– *Suspect's relationship with the victim*

Factor 10 in favour of prosecution in the Interim Policy provided for a higher likelihood of prosecution if the suspect was neither the spouse, partner, close relative or close

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[175] Seale (n173).

[176] Lee (n174).

[177] CPS, Starmer, 'Decision on Prosecution — The Death by Suicide of Daniel James' (ch1 n25) paras [6],[7],[16], [35]. See also text to n33.

[178] 'Public Consultation Exercise on the Interim Policy for Prosecutors' (n87) para [6.12].

[179] ibid [6.13].

personal friend of the victim,[180] whilst Factor 6 against prosecution provided for a lower likelihood of prosecution if the suspect was either the spouse, partner, close relative, or close personal friend of the victim.[181] Over 1,600 respondents raised concerns with these two factors. They aptly asserted that familial or other close personal relationships are not always supportive and could in some circumstances be antagonistic, manipulative or violent.[182] They also said that such factors could discriminate against a victim who does not have such close support available to them.[183] This was the very predicament experienced by Tony Nicklinson,[184] and more recently by Martin.[185] Both factors were duly removed from the DPP's Policy. Nevertheless, as discussed above, public opinion surveys in the UK show increasing support for family members to be able to lawfully assist in the suicides of their loved ones.

Based on the response from the public consultation, the DPP believed that the public interest factors in the DPP's Policy represents society's general moral yardstick to what it believed to be permissible suicide assistance.[186] It is argued however that the feedback from the public consultation, as it was conducted, does not reflect the prevailing morality or values in English society. There had been no thorough study or survey conducted to establish an objective, independent gathering and evaluation of data. It is unclear how members of the public were invited to participate in the consultation exercise, and whether there were any selection procedures involved. The DPP's method of gauging public opinion, by merely inviting members of the public to respond with views on the policy is not a sound method of collecting empirical data. The results from the public consultation were also not statistically sound in terms of size, as only an estimated 5,000 people responded to the consultation.[187]

2.2.4 *Effect of DPP's Policy*

The DPP's Policy attempts to clarify how prosecutorial discretion is exercised, by providing a list of factors that the DPP will take into account in deciding whether or not

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[180] ibid [2.10].

[181] ibid [6.18].

[182] ibid [2.10].

[183] ibid [6.19].

[184] *Nicklinson* (HC) (ch1 n8).

[185] *Nicklinson* (CA) (ch1 n10) [138].

[186] *Report of the Commission on Assisted Dying* (ch1 n51) 285.

[187] 'Public Consultation Exercise on the Interim Policy for Prosecutors' (n87) 39.

a prosecution for assisted suicide is in the public interest.[188] The fact that suicides which take place within England and Wales are included in the DPP's Policy makes the policy more significant than was originally anticipated by the House of Lords in *Purdy* which had only directed the DPP to provide clarity for those travelling overseas.[189] As observed by Lewis, '[the] DPP [has created] an expansive policy covering all assisted suicides rather than just those which take place in another more permissive jurisdiction.'[190] Pursuant to the DPP's Policy, a prosecution would be unlikely to be in the public interest where a person compassionately assists a loved-one, who has made a voluntary, clear, settled and informed decision to die.[191] The British public is generally in favour of the principle that a person should not be prosecuted for compassionately assisting another to commit suicide.[192] This is demonstrated in the findings of a 2010 YouGov poll for the *Daily Telegraph* newspaper, which showed that 82% of respondents supported the DPP's Policy on assisted suicide.[193] It is, however, argued that in respect of meeting the needs of society, the DPP's Policy itself is far from adequate for the following reasons.

The effect of relying upon the DPP's Policy is that investigations are only ever carried out to consider the victim's settled decision to die, and the suspect's motivation after the victim's death.[194] Thus, there are no prospective safeguards in place under the current model to protect those who seek an assisted suicide, but who might be vulnerable and feel under pressure from others to seek such assistance. The public-interest factors in the DPP's Policy have been designed to ensure that suicide assistance remains an activity carried out by amateurs or inexperienced individuals in England and Wales, as healthcare professionals are deterred from assisting patients.[195] They also deter any individuals or organisations from providing any expert information,[196] even to the extent

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[188] APPG, 'Bill consultation: Latest news' (ch1 n56).

[189] Lewis (n97) 119. Debbie Purdy's appeal merely focused on cases of suicide tourism.

[190] ibid 133.

[191] M Harper, 'Commons debates assisted suicide' (*the website of Mark Harper MP*,19 April 2012) <www.markharper.org/archives/759> accessed 30 July 2013.

[192] APPG, 'Bill consultation: Latest news' (ch1 n56).

[193] 'YouGov/Daily Telegraph Survey Results, 26th to 28th January 2010]'(YouGov 2010).

[194] APPG, 'Bill consultation: Latest news' (ch1 n56).

[195] Lewis (n97) 128.

[196] cf. In Germany, the *Deutsche Gesellschaft für Humanes Sterben* [German Society for Humane Death] provides information to those who are terminally ill and wanting to end their lives, while *Dignitate Deutschland* facilitates patients' contact with Dignitas in Switzerland. Both organisations are discussed in section 5.5.

of making such information available on a website,[197] and discourage the emergence of any assisted suicide facility[198] within England and Wales.[199] Thus, the DPP's Policy makes sure that it is extremely difficult to obtain meaningful or practical assistance with suicide within England and Wales.[200] This may actively encourage people to seek help in right-to-die organisations abroad, and to seek an assisted suicide sooner than they might otherwise, because of the need to travel abroad whilst they are able to do so.[201] In this manner, the DPP's Policy may succeed in keeping the number of assisted suicides which take place entirely within England and Wales relatively low.[202] However, if this is achieved at the cost of exporting suicidal Britons to a jurisdiction where an assisted suicide is easily available, then the law is less than satisfactory.[203]

The inadequacy of the DPP's Policy is also reflected in the recent 2013 decision of the Court of Appeal in *Nicklinson*:

> A list of factors which contains no clue as to how the discretion to grant or withhold consent will be exercised is not sufficient to meet the requirements of Article 8(2)[204]…If a list of relevant factors does not enable the person concerned to foresee, to a degree that is reasonable and adequate in the circumstances, the consequences of his action, then the Article 8(2) requirement is not satisfied.[205]

A concern with the DPP's Policy is that the discretion to prosecute assisted suicide cases under section 2(4) of the SA 1961 is applied according to an offence-specific policy, rather than legislation. If there is a change of DPP, then the application of the DPP's Policy may change. Thus, there remains considerable uncertainty with the type of

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[197] Public interest factor in favour of prosecution – DPP's Policy (ch1 n34) para 43(11): 'the suspect … encouraged or assisted the victim to commit or attempt to commit suicide by providing specific information via, for example, a website or publication'.

[198] Public interest factor in favour of prosecution – DPP's Policy (ch1 n34) para 43(16): 'the suspect was … a person involved in the management or as an employee … of an organisation or group, a purpose of which is to provide a physical environment … in which to allow another to commit suicide.' e.g. Right-to-die organisations, such as Dignitas in Switzerland, and suicide advocacy groups such as Compassion and Choices in Oregon, help facilitate the law on assisted suicide in those countries. These are discussed in sections 5.4 and 5.7.2.

[199] Mullock (n103) 449.

[200] ibid 468.

[201] ibid 450.

[202] Lewis (n97) 130.

[203] Mullock (n103) 452.

[204] art 8(2) (n25).

[205] *Nicklinson* (CA) (ch1 n10)[138]. See section 2.2.3 under *Healthcare professionals*.

conduct that will attract criminal prosecution for assisted suicide in England and Wales.[206]

The CPS has asserted that the offence of assisted suicide is no different from any other criminal offence in which the DPP has a similar discretion whether or not to prosecute.[207] This, however, is not convincing. In addition to the CCP,[208] the CPS applies the DPP's Policy when exercising its prosecutorial discretion on whether to prosecute for assisted suicide offences.[209] As the DPP's Policy states:

> [W]here there is sufficient evidence to justify a prosecution [for assisted suicide], prosecutors must go on to consider whether a prosecution is required in the public interest…[P]rosecutors must apply the public interest factors set out in the Code for Crown Prosecutors and the factors set out in [the DPP's Policy] in making their decisions. A prosecution will usually take place unless the prosecutor is sure that there are public interest factors tending against prosecution which outweigh those tending in favour.[210]

There is a difference in application between the DPP's Policy and the CCP. The DPP's Policy prescribes public interest factors for and against a prosecution that apply to all cases of assisted suicide, whereas the DPP's public interest discretion not to prosecute under the CCP is normally reserved for exceptional individual cases.

The DPP's Policy states that it neither 'decriminalises' the offence of encouraging or assisting suicide, nor provides an assurance that any person will be immune from prosecution.[211] Nevertheless, there have been no prosecutions for assisting a suicide since the DPP's Policy was published. This is notwithstanding the fact that there have been 68 cases referred to the CPS between 1 April 2009 and 1 March 2013.[212] It is accepted that the DPP's decision not to prosecute any of these referrals has undermined society's respect for the law.[213] There is now a public perception that any assisted suicides which meet the criteria stipulated by the DPP's Policy have been

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[206] *Report of the Commission on Assisted Dying* (ch1 n51) 299.

[207] 'Public Consultation Exercise on the Interim Policy for Prosecutors' (n87)[10.10]-[10.11].

[208] See CCP (ch1 n33).

[209] Ost (ch1 n122)512.

[210] DPP's Policy (ch1 n34) paras37,38.

[211] ibid para 6.

[212] 'Latest Assisted Suicide figures' (CPS, 5 March 2013) <www.cps.gov.uk/publications/prosecution/assisted_suicide.html> accessed 30 July 2013.

[213] *Report of the Commission on Assisted Dying* (ch1 n51) 93.

decriminalised.[214] This perception has been further bolstered by the House of Commons passing a motion to endorse the DPP's Policy on 27 March 2012.[215]

The chapter will now demonstrate that the current law on assisted death is inconsistent with the current law on end-of-life medical decisions in England and Wales. Despite assisted death being illegal in England and Wales, physicians are legally permitted to carry out certain end-of-life medical decisions. Three such situations are examined in the following section.

2.3 Current laws concerning end-of-life medical decisions

There are three situations in which end-of-life medical decisions are legally permitted – the administration of palliative medication with the foreseen although unintended consequence of the patient's death ('doctrine of double effect'), the withholding or withdrawal of life-sustaining treatment from competent patients who refuse treatment, and the similar withdrawal of such treatment from incompetent patients in their 'best interests'. These will be discussed in turn below. This section will also examine the case of *Re A*, where the English courts, relying on 'necessity', permitted an operation to separate a pair of conjoined twins that resulted in the death of one twin.[216] However, 'necessity' as a legal justification for ending one's life, remains restricted to the unusual facts of *Re A*.[217]

2.3.1 *Doctrine of double effect*

English case law permits a physician to administer a patient with palliative medication, with the intention of relieving pain and discomfort, even if it is foreseen that the patient's death will be hastened as a result of the high dosages of medication that are typically administered.[218] The English case that first highlighted this 'doctrine of double effect'[219] in medical practice was the 1957 murder trial of Dr Bodkin Adams, who had injected his 81-year-old patient with high doses of heroin and morphine.[220] Although

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[214] F Gibb, 'Prosecutors clear way for assisted suicides' *The Times* (London,5 September 2011).

[215] 'MPs back assisted dying guidelines' (*BBC News*,27 March 2012) <www.bbc.co.uk/news/uk-politics-17516998> accessed 19 August 2013.

[216] *Re A (Children) (Conjoined Twins:Surgical Separation)* (ch1 n6).

[217] Necessity is a legal defence for physician-assisted death in the Netherlands. See section 5.2.

[218] R Huxtable, 'Get out of jail free? The doctrine of double effect in English law' (2004)18 Palliative Medicine 62.

[219] See section 3.3.6.

[220] *R v Bodkin Adams* [1957] CrimLR 365.

Adams was acquitted of murder, the General Medical Council ('GMC') barred him from practising medicine for three years.[221] Mr Justice Devlin stated that:

> If the first purpose of medicine – the restoration of health – could no longer be achieved, there was still much for a doctor to do, and he was entitled to do all that was proper and necessary to relieve pain and suffering, even if the measures he took might incidentally shorten life by hours or perhaps even longer.[222]

It is the physician's intention which determines whether the doctrine of double effect constitutes a legal defence to murder.[223] Provided a physician demonstrated the intention to only relieve suffering, the fact that they might have foreseen that death was virtually certain to result from a high dosage of palliative medication does not matter.[224] It is argued that there is a contradiction between this doctrine and the elements of the law of murder. English courts have recognised that where a person foresees that death is a virtually certain consequence of their action, this would either amount to intention, or at least evidence of intention.[225] However, to maintain the legality of the doctrine of double effect, a legal distinction between 'foresight' and 'intention' has been created by the courts. As a result, the English courts have legally permitted what could be regarded as 'indirect euthanasia'. In this regard, it is concluded that the law is inconsistent in its approach to medical decisions with a 'double effect' and assisted death in England and Wales.

The doctrine of double effect was endorsed by the House of Lords in 1994 in Bland's case, where Lord Goff held that a physician may 'lawfully administer painkilling drugs, [in an incompetent patient's best interests], despite the fact that he knows that an incidental effect of that application will be to abbreviate the patient's life'.[226] Seale's 2004 national survey on end-of-life decisions, using the responses of 857 doctors in the UK, found the administration of palliative medication with possible life-shortening

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[221] C Hawkins, *Mishap or Malpractice?* (Medical Defence Union and Blackwell Scientific Publications 1985) 64-65.

[222] H Palmer, 'Dr Adams' Trial for Murder' (1957) Crim.L.R 365,375.

[223] SAM McLean, 'Legal and ethical aspects of the vegetative state' (1999)52 J Clin Pathol 490.

[224] Mullock (n103) 456.

[225] *R v Woollin* [1998] 4 All ER 103.

[226] Bland's case (ch1 n12) 867.

effect to be a widespread practice. An estimated 192,000 patients (out of 584,791 deaths) per annum were found to have their lives ended in this way.[227]

Rothschild's argument that the doctrine of double effect could be manipulated to covertly end a patient's life is a powerful one. Although a patient is not legally permitted to request lethal medication, if a lethal amount of palliative treatment is administered, it would be difficult to determine the legality of such actions.[228] In such cases the courts would have to determine whether the physician's intention was to end the patient's life, or to alleviate their pain. The findings of Seale's 2009 survey, on end-of-life decisions in the UK between 2007 and 2008, indicate the existence of such covert practices in England and Wales. Seale's survey showed that slightly less than one fifth of annual patient deaths in the UK are the result of the doctrine of double effect.[229] Of the 2,869 physicians who had presided over patient deaths in 2008, 17.1% of deaths had involved a medical decision with a 'double effect'. In 15.1% of these deaths the physicians reported 'knowledge of probable or certain hastening of end of life', and in 2.0% the physicians reported that they were even 'partly intending to end life'. This 2.0% of deaths where physicians had 'partly intended to end life' is evidence demonstrating the difficulty of determining the legality of medical decisions with a 'double effect'. It is accepted that in such cases doctors may have a 'double intention', an intention to not only relieve suffering but an intention to hasten death as well.[230]

This 'double intention' of doctors in relation to medical decisions with a 'double effect' was illustrated in the 1981 case of Dr Arthur.[231] Dr Arthur was charged with the attempted murder of a Down Syndrome child who also had other defects affecting his brain, heart and lungs. The doctor had ordered 'nursing care' only for the child, and administered a sedative which alleviated stress.[232] The child died of starvation three days later. Dr Arthur confessed to the police that the sedative was intended to both relieve the symptoms of the child's physical condition and to stop him wanting sustenance.[233]

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[227] C Seale 'National Survey of End-of-Life Decisions Made by UK Medical Practitioners' (2006)20(1) Palliative Medicine 3.

[228] A Rothschild, 'Just When You Thought the Euthanasia Debate Had Died' (2008)5 Bioethical Inquiry 69,74-75.

[229] Seale (n148).

[230] MA Branthwaite, 'The law looks at assisted dying' (2011)66 Thorax 347.

[231] *R v Arthur* (1981)12 BMLR 1.

[232] D Brahams, 'Acquittal of Paediatrician Charged After Death of Infant with Down Syndrome' (1981)2 Lancet 1101,1101.

[233] MJ Gunn and JC Smith, 'Arthur's case and the right to life of a Down's syndrome child' (1985) The Criminal Law Review 705.

However, the judge made no mention of Dr Arthur's potential homicidal intent during the summing up,[234] and the doctor was acquitted.[235] The law in respect of medical decisions with a 'double effect', involving critically ill infants, has been clarified by Lord Donaldson in the 1990 case of *Re J*:

> [D]octors and the court have to decide…whether, in the best interests of the child …a… decision as to medical treatment should be taken which as a side-effect will render death more or less likely… [T]he use of drugs to reduce pain will often be fully justified, notwithstanding that this will hasten the moment of death. What can never be justified is the use of drugs or surgical procedures with the primary purpose of doing so.[236]

The doctrine of double effect was rejected in the 1992 case of Dr. Nigel Cox. Dr. Cox's patient died after he gave her an intravenous injection of potassium chloride, a drug which has no pain-reducing qualities, but could cause cardiac arrest.[237] The patient was suffering from a severe case of rheumatoid arthritis. She was expected to die within a few days, but the pain had become so extreme that she pleaded for an injection to end her life.[238] The court found the physician to have intended to hasten his patient's death rather than to relieve the patient of pain and suffering.[239] Due to the uncertainty of the cause of death, Cox was charged with attempted murder rather than murder.[240] Although Cox was found guilty and the judge held that he had 'betrayed his unequivocal duty as a physician', he was merely penalised with a 12 month suspended prison sentence.[241] Cox was also not reprimanded by the GMC after being found guilty of serious misconduct.[242] Instead, when addressing Cox, the President of the GMC said, 'you acted in good faith in what you thought to be the best interests of your dying patient, and ... your purpose was to relieve her intolerable suffering by expediting her death'.[243]

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[234] ibid.

[235] D Brahams, 'Doctors in the Dock: the Last Sixty Years' (1992)60 Medico-Legal Journal 227,228.

[236] *Re J (A Minor) (Wardship: Medical Treatment)* [1990] 3 All ER 930, 938. See section 4.3.1.

[237] T Helme and N Padfield, 'Setting Euthanasia on the Level' (1993)XV(1) Liverpool L.Rev. 75,76. See also: C Dyer, 'Rheumatologist Convicted of Attempted Murder' (1992)305 BMJ 731.

[238] Dyer (ibid).

[239] The Honourable Mr. Justice Ognall, 'A Right to Die? Some Medico-Legal Reflection', (1994)62 Medico- Legal Journal 165,170.

[240] D Brahams, 'Euthanasia: Doctor Convicted of Attempted Murder' (1992)340 Lancet 782,782.

[241] 'The Final Autonomy' (1992)340 Lancet 757,758.

[242] RT Shepherd, Untitled, (1992)60 Medico-Legal Journal 227,229.

[243] D Claire, 'GMC tempers justice with mercy in Cox case' (1992)305 BMJ 1311.

In conclusion, the doctrine of double effect calls into question the legal and moral defensibility of the current English law on assisted death. Whilst physicians cannot lawfully respond to a direct request for assistance to die, English law upholds the doctrine of double effect and permits doctors to knowingly hasten a patient's death by relying on the fact that it is a mere side effect of palliative medication and not their intention to end life. Also, the cases of Dr Arthur and Dr Cox demonstrate that where physicians fail to rely on the doctrine of double effect to justify medical decisions hastening death, the English courts and the medical profession are lenient with such physicians if the reasons for such medical decisions are based on compassion.

2.3.2 *Competent patients refusing life-sustaining treatment*

In the 2002 case of *Re B*, the court held that physicians are not lawfully allowed to treat a competent patient who has refused life-sustaining treatment.[244] In this case, Ms B was a 44-year-old woman who had suffered a haemorrhage in her spinal column, leaving her paralysed from the neck down and dependent on a ventilator to breathe. Ms B instructed her physicians to switch off her life-sustaining ventilator, but they refused on the grounds that she was not competent. She then sought a court order to declare that the refusal was an unlawful trespass. The court found Ms B to be competent. Dame Elizabeth Butler-Sloss P considered that:

> I am…asked…to decide whether [Ms B]…is legally competent to make [the decision whether to require the removal of the artificial ventilation keeping her alive]…Unless the gravity of the illness has affected the patient's [mental] capacity, a seriously disabled patient has the same rights as the fit person to respect for personal autonomy.[245]

Dame Butler-Sloss further stated that those caring for Ms B 'should not confuse the question of mental capacity with the nature of the decision made by the patient,

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[244] *Re B (Adult: Refusal of Treatment)* (ch1 n42). Administering medical treatment without a patient's consent would be unlawful and amount to trespass, possibly leading to a criminal charge of assault or battery or a civil battery in the law of tort: Bland's case (ch1 n12) 864.

[245] *Re B (Adult: Refusal of Treatment)* (ch1 n42)[12],[94]. The court also stressed that for a competent patient to exercise autonomy to refuse treatment, they must be in possession of sufficient information regarding the nature, purpose and effects of the proposed treatment, and appreciate them and the consequences of their decision. For 'respect for autonomy', see section 3.3.4.

however grave the consequences', since Ms B's decision may 'reflect a difference in values rather than an absence of competence'.[246]

Keown argues that Ms B's request to her physicians to switch off the life-sustaining ventilator may effectively be regarded as a request for physician-assisted suicide. The decision in *Re B*, according to him, could amount to a judicial extension of the right to refuse treatment to the right to assisted suicide.[247] Keown's argument is not persuasive as competent patients have the absolute right to refuse treatment, 'notwithstanding that the reasons for making the choice are rational, irrational, unknown or non-existent'.[248] The English courts have also expressly stated that refusals of life-sustaining treatment do not amount to suicide.[249] As Lord Goff in Bland's case held:

> there is no question of the patient having committed suicide, nor therefore of the doctor having aided or abetted him in so doing. It is simply that the patient has, as he is entitled to do, declined to consent to treatment which might or could have the effect of prolonging his life, and the doctor has, in accordance with his duty, complied with his patient's wishes.[250]

It is submitted that the case of *Re B* demonstrates that English law does not recognise a competent person's right to die with assistance except to the extent that a person can achieve this goal by exercising their right to refuse treatment.[251]

It is argued that a comparison made between the cases of *Pretty*[252] (discussed above) and *Re B* demonstrates the inconsistency of the current English law on assisted death. Ms B, who was not terminally ill, was granted a court order which enabled her to die, whilst the terminally ill Mrs Pretty was denied a court order permitting her husband to assist her to travel to Switzerland, for an assisted suicide at Dignitas. Commentators have provided various ethical justifications for reconciling cases such as these. For example, Beauchamp and Childress consider that in cases such as *Re B* it is the underlying disease or injury that causes the patient's death rather than the discontinuance of

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[246] ibid [100].

[247] J Keown, 'The case of Ms B: suicide's slippery slope?' (2002)28 J Medical Ethics 238.

[248] *Re T (Adult: Refusal of Treatment)* [1992] 4 All ER 649,653.

[249] *Secretary of the State for Home Department v Robb* (1995) 1 All ER 677.

[250] Bland's case (ch1 n12) 864; *Re B (Adult: Refusal of Treatment)* (ch1 n42)[23].

[251] P Singer, 'Ms B and Diane Pretty: A Commentary' (2002)28 J Medical Ethics 234.

[252] *Pretty* (ECtHR) (n22).

treatment.[253] Pellegrino describes this as 'letting Nature take its course',[254] while McGee regards this as 'not taking control of death'.[255] Miller, however, convincingly argues that where life-sustaining treatment is withdrawn from patients like Ms B who are not terminally ill, the cause of death is both the underlying disease or injury and the withdrawal of treatment.[256] He also forcefully argues that if life-sustaining treatment is withdrawn from a terminally ill patient, it is reasonable to assume that death is caused by the disease, as life is merely prolonged by such treatment. Thus, relying on Miller's ethical reasoning, by switching off Ms B's life-sustaining ventilator, the physicians would have contributed to her death. The case of *Re B* demonstrates that a competent patient, dependent on life-sustaining treatment, may still have some control over the manner and timing of their death under the present law in England and Wales.

Thus, it is rightly contended by Brodowski that:

> there may be little distinction between the intent of a terminally ill patient who decides to remove her life support and one who seeks the assistance of a doctor in ending her life ... [as in] both situations, the patient is seeking to hasten a certain, impending death.[257]

Thus, if patients are able to end their lives by refusing life-sustaining treatment, it is morally indefensible that they are prevented from ending their lives more directly through lethal medication.[258] Many commentators argue that there is the risk of abuse should physician-assisted suicide be legalised. However, it is submitted that the same risks of abuse exist in cases where life-sustaining treatment is withheld or withdrawn. As correctly observed by Rothschild, there is no reason why patients and particularly the old and vulnerable,[259] cannot be coerced or pressured into having treatment withheld or withdrawn which may otherwise save or extend their lives.[260]

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[253] TL Beauchamp & JF Childress, *Principles of Biomedical Ethics* (5th edn, OUP 2001)140.

[254] ED Pellegrino, 'Doctors Must Not Kill' (1992)3 J Clinical Ethics 95,98.

[255] A McGee, 'Finding a Way through the Ethical and Legal Maze: Withdrawal of Medical Treatment and Euthanasia' (2005)13(3) Med.Law.Rev. 357. See section 3.3.1.

[256] FG Miller, 'Assisted Suicide Compared with Refusal of Treatment: A Valid Distinction?' (2000)132 Ann Intern Med 470

[257] H Brodowski, 'Suffering Against Their Will: The Terminally Ill and Physician Assisted Suicide--a Constitutional Analysis' (1996)12(1) J.Civ.Rts.&Econ.Dev 171,188.

[258] R Magnusson, 'The Future of the Euthanasia Debate in Australia' (1996)20 MULR 1108,1126.

[259] See section 3.4.6.

[260] Rothschild (n228) 73.

2.3.3 *Incompetent patients unable to refuse life-sustaining treatment*

English law permits physicians to withdraw or withhold life-sustaining treatment from incompetent patients, if they determine this to be in the patients' best interests. In 1994, the House of Lords in Bland's case held that a physician's duty towards a patient in a permanent vegetative state ('PVS') does not extend to prolonging their life at all costs.[261] In this case, Bland was a 17-year-old patient who had sustained injuries from being crushed and deprived of oxygen in the 1989 Hillsborough football stadium disaster. These injuries had led to irreversible brain damage, and had caused Bland to be in a state of PVS for four years. The House of Lords held that the provision of artificial nutrition and hydration ('ANH') was futile, burdensome and of no benefit to Bland,[262] and permitted the withdrawal of ANH from him, causing him to starve to death.[263] As Lord Goff held, 'if the treatment is futile ... it is no longer in the best interests of [Bland] to continue it.'[264] His Lordship was of the view that there was no real difference between turning off a life support machine and never providing it in the first place.[265] As the House of Lords had to draw a distinction between such withdrawal of treatment and murder, the lawful withdrawal of treatment was regarded as an 'omission' to provide treatment which there was no duty to provide,[266] and Bland's death was 'regarded in law as exclusively caused by the injury or disease to which his condition [was] attributable'.[267]

Brazier argues that 'The *legerdemain* by which their Lordships classified removal of a feeding tube as an omission not an act provokes charges of covert legalisation of euthanasia.'[268] Even Lord Lowry in Bland's case expressly recognised that the case might be seen as an example of 'euthanasia in action'.[269] He further stated that the 'act' and 'omission' distinction was 'a distinction without a difference: the intention is to terminate life'.[270] Similarly, Lord Mustill observed in Bland's case that, to absolve the physicians from causing the death of a patient on the basis that it was an omission and

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[261] Bland's case (ch1 n12) 823 (Butler-Sloss LJ).

[262] See section 4.3.3.

[263] Bland's case (ch1 n12) 869.

[264] ibid 871. The 'best interests' assessment has since been adopted in the MCA 2005.

[265] ibid 866.

[266] ibid 858-9 (Lord Keith),865-6,873 (Lord Goff),887,892-93,897-8 (Lord Mustill).

[267] ibid 866 (Lord Goff).

[268] M Brazier, *Medicine, Patients and the Law* (3rd edn, Penguin Books 2003) 450.

[269] Bland's case (ch1 n12) 877.

[270] ibid 877.

not an act was ‘morally and intellectually dubious’, ‘illogical’, and served only to emphasise ‘the distortions of a legal structure which is already both morally and intellectually misshapen’.[271] Lord Browne-Wilkinson in Bland’s case admitted that the Bland decision was irrational:

> How can it be lawful to allow a patient to die slowly, though painlessly, over a period of weeks from lack of food but unlawful to produce his immediate death by a lethal injection, thereby saving his family from yet another ordeal to add to the tragedy that has already struck them?[272]

It is contended that the House of Lords’ approach to the distinction between ‘act’ and ‘omission’ is artificial as their Lordships themselves conceded. Whilst a discontinuation of treatment is regarded an ‘omission’, it is hard to rationalise how the ‘removal’ of treatment such as life support machines and feeding tubes can be considered an ‘omission’. As soundly asserted by Beauchamp, when a feeding tube is removed from a patient, it is the withdrawal of treatment that directly leads to death by starvation and dehydration, rather than death being the result of an underlying illness or disease.[273] McLean forcefully argues that the House of Lords’ authorisation of the removal of ANH from Bland amounted to the endorsement of non-voluntary euthanasia.[274] Similarly, Andrews cogently asserts that:

> [w]e seem to be progressing down the road of accepting [non-]voluntary euthanasia before voluntary euthanasia has been accepted legally. It is unlikely that starvation would be regarded as an acceptable way of assisting dying in voluntary euthanasia, so should we even consider this method for [non-]voluntary euthanasia?[275]

Seale’s research on end-of-life decisions in the UK between 2007 and 2008 shows how prevalent such omissions are. Seale found that over one fifth of annual deaths involved an omission to treat the patient, both competent and incompetent. 21.8% of deaths involved the withdrawal or withholding of life-sustaining treatment, with the

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[271] ibid 898,895,887.

[272] ibid 885.

[273] TL Beauchamp, ‘The Medical Ethics of Physician-Assisted Suicide’ (1999)25 J Medical Ethics 437.

[274] McLean (n223). ‘Non-voluntary euthanasia’ is explained in text to ch1 n98.

[275] K Andrews, ‘Recovery of Patients after Four Months or More in the Persistent Vegetative State’ (1993) 306 BMJ 1597, 1602. ‘Voluntary euthanasia’ is explained in ch1 n7.

physician's knowledge or intention that this would result in the patient's death.[276] In 16.8% of the deaths, the physician made the decision to withdraw or withhold treatment with 'knowledge of probable or certain hastening of end of life'. In 4.9% of the deaths, the decision was made 'with explicit intention of hastening end of life'.

It is argued that the current prohibition on assisted death in England and Wales is inconsistent with such end-of-life medical decisions involving incompetent patients. It is permissible to withdraw or withhold life-sustaining treatment from an incompetent patient, without their prior consent, with the intention to end their life. Yet, it is illegal to assist a person to end their life based on their competent and autonomous decision to die.

Over 10 years after Bland's case, it was reiterated in the 2005 case of *Burke* that treatment which placed an intolerable burden on an incompetent patient may be withdrawn if it is clinically determined to be futile and unlikely to be in the patient's best interests. The Court of Appeal in *Burke* also held that legally competent patients cannot demand that life-sustaining treatment be administered in the event that they cease to be legally competent.[277] In *Burke*, the patient was dying from cerebellar ataxia, a progressive degenerative brain condition. His condition was expected to deteriorate to a point at which he would lose his physical abilities, including the ability to swallow and communicate. The patient was concerned that the GMC's guidance on the withholding and withdrawal of life-sustaining treatment[278] would result in him being deprived of ANH once he was no longer able to express his wishes. He challenged the legality of this guidance, by invoking Articles 2,[279] 3[280] and 8[281] of the ECHR. The Court of Appeal held that the withdrawal or withholding of ANH may be appropriate when physicians determine that the burdens outweigh the benefits of treatment. The Court further stated that the 'best interests' test is an objective one, and that what physicians consider to be in a patient's best interests may conflict with the patient's own wishes.

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[276] Seale (n148).

[277] *R (Burke) v General Medical Council* [2005] EWCA 1003,[29]-[30].

[278] *Withholding and Withdrawing Life-prolonging Treatments: Good Practice in Decision-making* (GMC,August 2002) para81 provides 'Where death is imminent and artificial hydration and/or nutrition are already in use, it may be appropriate to withdraw them if it is considered that the burdens outweigh the possible benefits to the patient.' Since Burke's case, this guidance has been superseded by a corresponding provision: *Treatment and care towards the end of life: good practice in decision making* (GMC,May 2010) para123.

[279] 'The right to life'.

[280] 'The right not to be subjected to inhuman or degrading treatment'.

[281] 'The right not to have his physical and psychological integrity and dignity infringed under the right to respect for private and family life'.

Based on *Burke*, physicians must provide ANH to a patient who is competent. However, when a patient is no longer competent, the provision of ANH is purely a medical matter to be determined by physicians by acting in the patient's best interests.

The cases of *Bland* and *Burke* demonstrate that English law is morally indefensible. When a patient becomes incompetent, physicians are allowed to make paternalistic[282] medical decisions on the provision of life-sustaining treatment to them. After weighing the burdens and benefits of treatment, and determining the best interests of the patient, physicians may withdraw or withhold life-sustaining treatment from incompetent patients. Yet, a competent patient is not allowed to determine their own best interests and end a life of unbearable pain and suffering with the assistance of a willing physician.

– *Advance decisions*

Under common law, English courts have recognised that an advance refusal of treatment by a patient who has subsequently become incompetent is as valid as a contemporaneous refusal of treatment by a competent patient.[283] However, prior to the MCA 2005, the courts had approached such advance refusals 'with a bias against their validity and applicability, unless they are clear and unambiguous'.[284] Since 2007, life-sustaining treatment may be withdrawn or withheld from an incompetent patient pursuant to an advance decision made under the MCA 2005 when the patient was competent.[285] Thus, advance decisions may effectively enable competent patients to extend their autonomy[286] and right to self-determination,[287] to make decisions concerning the manner and time of their death for when they are no longer competent.

It is, however, argued that advance decisions may lack the moral force of contemporaneous decisions.[288] A person's wishes and feelings may not remain the same

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[282] See section 3.3.8.

[283] *Re T (Adult: Refusal of Treatment)* (n248).

[284] S Michalowski, 'Advance Refusals of Life-Sustaining Medical Treatment: The Relativity of the Absolute Right' (2005)68 Med.L.Rev 958,981.

[285] An advance refusal does not apply to 'life-sustaining treatment' unless verified by a written statement to the effect that it is to apply even if life is at risk: MCA 2005 sub-ss 25(5)-(6).

[286] See section 3.3.4.

[287] See section 3.3.2.

[288] A Buchanan, 'Advance directives and the personal identity problem' (1998)17 Philosophy and Public Affairs 277.

following their incapacity.[289] As Donnelly cogently argues, a competent person may have clear preferences regarding their life but these might change following a loss of capacity. A person who, while competent, expresses a strong preference that they would not wish to live with profound disabilities, may be contented in a state which would have previously seemed unbearable to them.[290] Nevertheless, an advance decision made pursuant to the MCA 2005 will not be followed if there are 'reasonable grounds' for believing that circumstances exist which the person did not anticipate at the time of making the advance decision, and which would have affected the decision had the person anticipated them.[291]

– *Best interests under the Mental Capacity Act 2005 (MCA 2005)*

Since 2007, decisions made on behalf of incompetent patients have to be made based on an assessment of the patients' best interests under the MCA 2005.[292] The MCA 2005 provides a checklist of factors that must be considered in determining what would be in the patient's best interests.[293] However, as the checklist is not exhaustive, other factors will also be considered.[294] In respect of the provision of life-sustaining treatment, the MCA 2005 provides that:

> All reasonable steps which are in the person's best interests should be taken to prolong their life. There will be a limited number of cases where treatment is futile, overly burdensome to the patient or where there is no prospect of recovery. In circumstances such as these, it may be that an assessment of best interests leads to the conclusion that it would be in the best interests of the patient to withdraw or withhold life-sustaining treatment, even if this may result in the patient's death.[295]

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[289] R Dresser, 'Dworkin on Dementia: Elegant Theory, Questionable Policy' [1995] Hastings Cent.Rep. 32.

[290] M Donnelly, 'Best Interests, Patient Participation And The Mental Capacity Act 2005' (2009)17 Med.L.Rev 1,24.

[291] MCA 2005 sub-s 25(4)(c).

[292] ibid sub-s 1(5). Refer to ss 2-3 for the definition of a person who lacks capacity. See section 2.2.3 under *Victim's mental capacity*.

[293] MCA 2005, Code of Practice paras 5.5-5.6.

[294] ibid, Code of Practice para5.47.

[295] ibid, Code of Practice para5.32. This echoes the House of Lords' decision in Bland's case (ch1 n12).

The MCA 2005 specifically states that the decision-maker must not, in considering whether the withdrawal or withholding of life-sustaining treatment is in a person's best interests, be motivated by a desire to bring about their death.[296]

The MCA 2005 also provides:

> As with all decisions, before deciding to withdraw or withhold life-sustaining treatment, the decision-maker must consider the range of treatment options available to work out what would be in the person's best interests. All the factors in the best interests checklist should be considered, and in particular, the decision-maker should consider any statements that the person has previously made about their wishes and feelings about life-sustaining treatment.[297]

It is submitted that by recognising a person's past wishes and feelings,[298] views,[299] beliefs and values[300], the MCA 2005 promotes the autonomy of incompetent patients. As Dworkin observes, by providing a space for past preferences, it seeks to give effect to the individual's 'right to a life structured by his own values'.[301]

It is argued that a 'best interests' assessment which recognises past preferences contains a strong element of the 'substituted judgement' standard.[302] Thus, the MCA 2005 recognises the dicta of Hoffman LJ in Bland's case which suggested applying a 'substituted judgement' standard for Bland:

> [t]he patient's best interests would normally also include having respect paid to what seems most likely to have been his own views on the subject. To this extent I think that what the American courts have called 'substituted judgement' may be subsumed within the English concept of best interests.[303]

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[296] ibid sub-s 4(5).

[297] ibid, Code of Practice para5.32.

[298] ibid sub-s 4(6)(a).

[299] ibid, Code of Practice para5.41.

[300] ibid sub-s.4(6)(b), Code of Practice para5.46.

[301] R Dworkin, *Life's Dominion: An Argument About Abortion, Euthanasia, and Individual Freedom* (Alfred A Knopf 1993) 224.

[302] Law Commission, *Mental Incapacity: Item 9 of the Fourth Programme of Law Reform: Mentally Incapacitated Adults* (Law Com No 231 1995), para3.25.

[303] Bland's case (ch1 n12) 833.

It is accepted that the 'substituted judgement' standard under the MCA 2005 is closer to an autonomy based standard[304] than the 'objective' best interests standard under common law.[305]

In October 2013, the Supreme Court decision of *Aintree University Hospitals NHS Foundation Trust v James* (the *Aintree NHS Trust* case)[306] affirmed that the best interests assessment under the MCA 2005 is one that requires a patient's subjective interests to be considered, an assessment which is line with a 'substituted judgement' standard. The Court also noted that although:

> The purpose of the best interests test is to consider matters from the patient's point of view. That is not to say that his wishes must prevail, any more than those of a fully capable patient must prevail. We cannot always have what we want.[307]

The *Aintree NHS Trust* case will be discussed in further detail in Chapter Four.

As observed by Joyce, the substituted judgement standard is included in the best interests assessment under the MCA 2005, to whatever extent the views or wishes of the patient when they had capacity are known. However, where patient's wishes or preferences are not known, the best interests assessment involves the weighing up of a range of factors to decide what is, on balance, best for the person.[308] In such circumstances, the 'objective' best interests assessment may be applied by physicians and the courts. Besides the wishes or preferences of the person, the views of others like family members and carers may also be taken into account if it can help determine what is in a patient's best interests.[309] However, it is argued that close friends or family members may not always know the past preferences or relevant beliefs and values of an incompetent person.[310] Thus, in these cases, the MCA 2005 cannot guarantee respect for what an incompetent patient's earlier autonomous decision would have been.

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[304] JK Mason et al, *Law and medical ethics* (6th edn, LexisNexis (UK) Ltd 2003), 519.

[305] A Buchanan and DW Brock, 'Medical Decision Making for the Demented and Dying: Deciding for Others' (1986) 64(2) Milbank Quarterly 17, 57.

[306] *Aintree University Hospitals NHS Foundation Trust v James* [2013] UKSC 67 ('*Aintree NHS Trust* case').

[307] ibid [45].

[308] T Joyce, *Best Interests: Guidance on determining the best interests of adults who lack the capacity to make a decision (or decisions) for themselves [England and Wales]: A report published by the Professional Practice Board of the British Psychological Society* (2007) 43.

[309] MCA 2005 sub-s 4(7). See further discussion in section 4.3.4.

[310] Donnelly (n290) 26.

For cases such as *Bland* involving a patient in a PVS, the courts have indicated that when considering the 'best interests' of a patient in a PVS under the MCA 2005, no balancing exercise need be undertaken because continued treatment will never be in such a patient's 'best interests'.[311]

A review of cases under the MCA 2005 indicates there remain at least three areas where the details the MCA's application are still to be resolved. The first area concerns the determination of a patient's 'best interests' under the MCA 2005, and how to reconcile this with the common law principle that a physician should not be compelled to treat a patient. This was considered in *An NHS Trust v L* (L's case).[312]

L's case involved an application by an NHS Trust for a declaration that it would not be in the best interests of L, an incompetent patient, to receive active resuscitation in the event that he should require it due to a cardiac arrest or similar deterioration. L was in a 'minimally conscious state' after suffering a heart attack, with no prospect of further improvement. In the event of a further cardiac arrest, L's condition was likely to deteriorate further if revived, and would at best be returned to its current state of minimal consciousness.

The judge in L's case, Moylan J, noted that the voice given to a patient's autonomy under the MCA 2005 continues to be constrained by the principle that 'doctors cannot be required to provide treatment which is contrary to their professional judgment'[313]. In reconciling this principle with the MCA 2005, Moylan J further noted (i) that under the MCA 2005 'there needs to be a choice of treatment options. If there are no treatment options, then the court has no effective choice to make',[314] and (ii) that '[t]hey must be treatments which would not require medical professionals to act in a way which was contrary to their professional clinical judgment'.[315] Moylan J stated that in his own view, there were no such treatment options in L's case, as there was only one treatment option which was not contrary to professional clinical judgment. This was the option of not reviving L, should L require it.[316] Somewhat surprisingly, Moylan J then stated that '[h]owever, as none of the parties support this conclusion, I now turn to the balancing

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[311] *In re M (Adult Patient) (Minimally Conscious State: Withdrawal of Treatment)* [2011] EWHC 2443 (Fam) at [102] and [64]. Baker J (*obiter*) referring to Lord Goff's judgment in Bland's case (ch1 n12) 868-869.

[312] *An NHS Trust v L* [2013] EWHC 4313 (Fam) ('L's case').

[313] ibid [78].

[314] ibid [113].

[315] ibid [116].

[316] ibid [117].

exercise [under the MCA 2005]'.[317] It is unclear whether Moylan J felt obliged to do this because he was constrained by the parties' submissions, or whether he merely chose to do this in order to remove any doubt about either the outcome, or about how the MCA 2005 is to be applied.

As required under the MCA 2005, Moylan J balanced all of the factors pointing both in favour and against the provision of cardiopulmonary resuscitation ('CPR') to L. In doing so, he considered both the evidence of L's wishes, as well as the physicians' objective assessment of L's likely quality of life. As a factor in favour of CPR, Moylan J accepted evidence from the family that L would 'find the current state and possibly a future worse state as giving an acceptable quality of life'.[318] As a factor against CPR, Moylan J considered that 'Even though it might be acceptable to Mr L, he has a very poor quality of life which is likely significantly to deteriorate in the event of a further cardio-respiratory arrest or other serious deterioration in his health'.[319]

Given Moylan J's view that a balancing of factors under the MCA 2005 was not required, it is not surprising that Moylan J's assessment when applying the MCA 2005 was that the clinical judgment of the doctors still prevailed. He concluded in favour of the NHS Trust's application. The fact that all parties to this case disagreed with Moylan J, and asserted that multiple treatment options did exist in this case,[320] may indicate that the full mechanics are yet to be ironed out for reconciling the MCA 2005 with the common law principle that a physician's clinical views about futile treatment are sacrosanct.

A second apparent unresolved area of the MCA's application concerns the weight that is to be given under the MCA 2005 to the expressed wishes of a patient who lacks full capacity. This arose in the 2012 case of *A Local Authority v E* (E's case),[321] and in the 2013 case of *A NHS Trust v Dr. A* (Dr. A's case).[322]

E's case involved a 32-year-old patient (E) who suffered from 'a triad of anorexia, alcoholism and personality disorder'. Tragically, all three conditions stemmed from E suffering sexual abuse as a child. During the preceding six years, E had been placed

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[317] ibid [117].

[318] ibid [121].

[319] ibid [122].

[320] ibid [88]-[89].

[321] *A Local Authority v E* [2012] EWHC 1639 (COP) ('E's case').

[322] *A NHS Trust v Dr. A* [2013] EWHC 2442 (COP) ('Dr. A's case').

four times in an eating disorder unit, and once in an alcohol treatment unit.[323] E was now in a palliative care unit after refusing to eat, or receive any treatment or nourishment. She had also signed a document stating that she did not want to be resuscitated or to be given any medical intervention to prolong her life.

A question considered in E's case by Jackson J was 'Does E at this point have the mental capacity to make decisions about her treatment?'[324] He held that:

> There is no doubt that E has an impairment of, or a disturbance in the functioning of, the mind or brain in the form of her anorexia. Equally it is clear that in terms of MCA s. 3(1) she can understand and retain the information relevant to the treatment decision and can communicate her decision.[325]

However, in holding that E lacked capacity, Jackson J then stated that:

> there is strong evidence that E's obsessive fear of weight gain makes her incapable of weighing the advantages and disadvantages of eating in any meaningful way. For E, the compulsion to prevent calories entering her system has become the card that trumps all others. The need not to gain weight empowers all other thoughts.[326]

He further held that:

> A secondary reason for the conclusion that E lacks capacity is that she is now subject to strong sedative medication and is in a severely weakened condition. She is, as her parents described it, in a '*drug haze*'.[327]

Although Jackson J determined that E lacked capacity, when considering 'The advantages and disadvantages of each course of action [that] must be balanced out',[328] he considered that the following two factors were in favour of continued palliative care as a treatment option — 'It reflects E's wishes', and 'it reflects E's personal

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[323] E's case (n321) [20].

[324] ibid [46].

[325] ibid [48]. See MCA 2005 s2.

[326] ibid [49]. See MCA 2005 s3.

[327] ibid [50].

[328] ibid [114].

autonomy'.[329] The consideration of these factors despite E being held to lack capacity appears to be somewhat contradictory.

Dr. A's case includes a similar apparent contradiction. The case involved an Iranian doctor (Dr. A), who was resisting deportation from the UK with a hunger strike, whilst also showing symptoms of delusions which called into question his capacity to make rational decisions. In determining whether it would be in Dr. A's best interests to grant a declaration which would allow for the forcible provision of nutrition and hydration, Baker J applied the balance sheet approach.[330] As an argument against force feeding, Baker J considered that '[Dr. A's] hunger strike... should be respected as an aspect of his personal autonomy'[331] but then later noted that that 'in deciding what weight to ascribe to those wishes, it is of course relevant that this court has concluded that [Dr. A] lacks capacity to use and weigh up information relevant to a decision'.[332] As noted by Richardson:

> The MCA does not ... indicate the weight to be given to the wishes of a person without capacity, nor how they are to be assessed against the court's more general assessment of best interests.[333]

This further indicates that in some aspects of end-of-life medical decisions, the application of the MCA 2005 is still yet to be refined.

A third apparent unresolved area of the MCA's application concerns a so-called 'Catch 22 situation' that arose in E's case. Jackson J acknowledged that 'a person with severe anorexia may be in a Catch 22 situation regarding capacity, namely, that by deciding not to eat, she proves that she has no capacity at all'.[334] In this 'Catch 22', a patient seeks to rely on their absolute autonomous right as a competent person to refuse treatment. As noted above, this right exists 'however grave the consequences'.[335] Yet, as noted by Jackson J, the patient's attempt to exercise this right then also forms the basis for impugning their competency, and hence their right to autonomy.

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[329] ibid [115].

[330] Dr. A's case (n322) [50]-[52]. For the balance sheet approach, see text to n308.

[331] ibid [52].

[332] ibid [54].

[333] G Richardson, 'Mental Capacity in the Shadow of Suicide: What Can the Law Do?' (2013)9(1) Int J Law Context 87, 97.

[334] E's case (n321) [53].

[335] See text to n246.

Coggon likens E's case to an earlier case, *X NHS Trust v T (Adult Patient: Refusal of Medical Treatment)* (T's case),[336] in which a patient (T) was held to lack the capacity to refuse a blood transfusion, because she had refused the transfusion in the belief that her own blood was 'evil'.[337] Comparing T's case to E's case, Coggon notes that, 'in both cases, the patients are conscious decision-makers, but are ruled to lack capacity on the basis of the reasons that underpin their choices'.[338] Coggon then contrasts this with other cases in which the refusal of treatment or food due to religious or other conscientious beliefs was upheld, with no impugnation of the patient's capacity. He concludes that there is currently no satisfactory means of ascertaining 'which values are worthy of respect, and which ones of themselves indicate that the patient should be judged to lack capacity'.[339]

In summary, the cases of L, E and Dr. A demonstrate that the application of the MCA 2005 still requires further clarification, particularly in relation to, i) the determination of an incompetent patient's 'best interests', ii) the weight to be given to the expressed wishes of a patient who lacks full capacity, and iii) the determination of whether or not a patient lacks capacity based upon the rationale for their conscious decisions.

2.3.4 *Necessity*

The moral and legal defensibility of the law on assisted death in England and Wales was tested even further by the case of *Re A* in 2000.[340] In this case, the Court of Appeal allowed a surgical separation of twins, which resulted in the intended death of one twin, to enable the survival of the other. The conjoined twins, Jodie and Mary, were born joined at the lower abdomen. Mary depended on Jodie's heart and lungs to receive and use the latter's oxygenated blood.[341] This dependence by Mary on Jodie was expected to ultimately cause Jodie's heart to fail. If the twins were surgically separated, Jodie had a good prospect of a healthy and normal life, but Mary was certain to die within minutes. The Court of Appeal granted an application by the hospital for a declaration that it could lawfully carry out the surgical separation. The Court had to address whether the surgery,

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[336] [2004] EWHC 1279 (Fam).

[337] J Coggon, 'Commentary: Anorexia nervosa, Best Interests, and the patient's human right to "a wholesale overwhelming of her autonomy"' (2014) 22(1) Med L Rev 119, doi:10.1093/medlaw/fwt031 first published online 5 November 2013.

[338] ibid p10.

[339] ibid p12.

[340] *Re A (Children) (Conjoined Twins: Surgical Separation)* (ch1 n6).

[341] ibid 1016 (Ward LJ).

carried out in the knowledge that it was certain to result in Mary's immediate death, would amount to murder. The Court noted that since the physicians foresaw that the severance of the common aorta was certain to cause Mary's death, the physicians intended to kill Mary,[342] 'even though they may not have any desire to achieve that result'.[343] The Court emphasised that the separation procedure was only valid because of the unique facts involved in the case.

Brooke LJ noted that it was impossible to act simultaneously in the 'best interests' of both twins, agreeing that the 'sacrificial separation operation' was permissible on the basis that Jodie's interests should be preferred, given that Mary was 'sadly, self-designated for a very early death'.[344] Ward LJ stated that, 'Given the conflict of duty [between the twins] I can see no other way of dealing with it than by choosing the lesser of the two evils and so finding the least detrimental alternative.'[345] Ward LJ balanced the benefits of the operation to separate the twins, and held that this fell in favour of Jodie, as Mary would die either with or without operation.[346] He observed that the physicians owed a duty to defend Jodie from the threat of fatal harm which arose from the physical burden imposed by Mary.[347] He stated:

> I can see no difference in essence between…legitimate self-defence and the doctors coming to Jodie's defence and removing the threat of fatal harm to her presented by [Mary]. The availability of such a plea of quasi-self-defence, modified to meet the quite exceptional circumstances nature has inflicted on the twins, makes intervention by the doctors lawful.[348]

Brooke LJ applied the doctrine of necessity to facts of the case. He said:

> there are three necessary requirements for the application of the doctrine of necessity: (i) the act is needed to avoid inevitable and irreparable evil; (ii) no more should be done than is reasonably necessary for the purpose to be achieved; (iii) the evil inflicted must not be disproportionate to the evil avoided. Given that the principles of modern family law point irresistibly to

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[342] See *Woollin* (n225). See also text to n225.

[343] *Re A (Children) (Conjoined Twins: Surgical Separation)* (ch1 n6) 1012 (Ward LJ),1029 (Brooke LJ).

[344] ibid 1051-1052.

[345] ibid 1006.

[346] ibid 1010.

[347] ibid 1016-1017.

[348] ibid 1017.

> the conclusion that interests of Jodie must be preferred to the conflicting interests of Mary, I consider that all three of these requirements are satisfied in this case.[349]

The case of *Re A* further demonstrates, albeit on very narrow and special facts, the legal inconsistency in the law on the prohibition of assisted death in England and Wales. In *Re A*, physicians were allowed to carry out a medical procedure that resulted in Mary's death. The decision was not a medical decision involving the 'acts and omissions' distinction or a 'double effect'. The Court of Appeal relied on the doctrine of necessity to differentiate the case from euthanasia, and allowed the surgical separation. The Court also stated that the application of the doctrine of necessity was restricted to the unique facts of *Re A.* As stated in its judgment:

> Lest it be thought that this decision could become authority for wider propositions, such that a doctor, once he has determined that a patient cannot survive, can kill the patient, it is important to restate the unique circumstances for which this case is authority. They are that it must be impossible to preserve the life of X without bringing about the death of Y, that Y by his or her very continued existence will inevitably bring about the death of X within a very short period of time, and that X is capable of living an independent life but Y is incapable under any circumstances (including all forms of medical intervention) of viable independent existence.[350]

As noted previously, the case of *Nicklinson* has more recently sought to argue a defence of necessity in cases of euthanasia with such arguments so far having been rejected by the courts.[351]

In informing the current reform agenda for England and Wales, the chapter will now examine Bills which have been recently tabled in Parliament to legalise assisted death in England and Wales. The section will also consider recommendations for a future law on assisted death made by the House of Lords' Select Committee on the Assisted Dying for the Terminally Ill Bill 2004, and the Commission on Assisted Dying in 2012.

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[349] ibid 1051.

[350] ibid 1018 (Ward LJ).

[351] See section 1.1.1, and section 2.2.2 under *Tony Nicklinson*.

2.4 A review of recent reform attempts

There have been repeated calls for reform of the law on assisted death in England and Wales. Between 2003 and 2006, three attempts were made to legalise assisted deaths for the terminally ill. These attempts were made through the Patient (Assisted Dying) Bill in 2003,[352] the Assisted Dying for the Terminally Ill Bill 2004,[353] and the Assisted Dying for the Terminally Ill Bill 2005.[354] All were introduced in the House of Lords by Lord Joffe. In respect of the second Bill, a Select Committee, formed by the House of Lords to review the Bill ('Select Committee'), published a report ('2004 HL Select Committee Report') on the legal and ethical issues on assisted dying, and made recommendations for any future Bills.[355] Lord Falconer also made two separate attempts at amending the law on assisted death. During the passage of the Coroners and Justice Bill 2009, Lord Falconer proposed an amendment to the law on assisted suicide, which would have expressly allowed competent adults to travel abroad for an assisted suicide. In 2010, Lord Falconer became the Chairman of the Commission on Assisted Dying ('the Commission'), an unofficial body which was established and funded by private campaigners to evaluate the strengths and weaknesses of the present law following the publication of the DPP's Policy, and to explore a possible framework for legalising assisted death.[356] Based on the recommendations of the Commission's 2012 Report, the All-Party Parliamentary Group on Choice at the End of Life[357] drafted a Bill together with Dignity in Dying[358]. After the Bill went through a public consultation exercise, Lord Falconer made amendments to it, and introduced it as the Assisted Dying Bill 2013 in May 2013 in the House of Lords.[359] The Bills mentioned here, along with the recommendations of the 2004 HL Select Committee Report, and of the Commission's 2012 Report, will be examined below.

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[352] Patient (Assisted Dying) HL Bill (2002-03) 37 ('PAD Bill 2003').

[353] ADTI Bill 2004 (ch1 n48).

[354] Assisted Dying for the Terminally Ill HL Bill (2005-06) 36 ('ADTI Bill 2005').

[355] 2004 HL Select Committee Report, Vol I (ch1 n49) para 269.

[356] 'The Commission on Assisted Dying' (*Demos*, 2012) <www.demos.co.uk/publications/thecommissiononassisteddying> accessed 23 July 2013. The Commission included members with expertise in law, medicine, social care, mental health, palliative care, theology, disability and policing.

[357] APPG on Choice at the End of Life (ch1 n52).

[358] Dignity in Dying (ch1 n35).

[359] AD Bill 2013 (ch1 n57).

2.4.1 *Patient (Assisted Dying) Bill 2003*

In 2003, Lord Joffe introduced a Private Member's Bill, the Patient (Assisted Dying) Bill 2003 ('PAD Bill 2003') in the House of Lords. The PAD Bill 2003 would have enabled a competent adult who is suffering unbearably as a result of a terminal or serious, incurable and progressive illness to receive medical assistance to die at their own considered and persistent request.[360] The PAD Bill 2003 would have allowed a physician to undertake either assisted suicide or euthanasia. The Bill did not proceed beyond its Second Reading.

2.4.2 *Assisted Dying for the Terminally Ill Bill 2004*

In January 2004, Lord Joffe introduced a second Private Member's Bill, the Assisted Dying for the Terminally Ill Bill 2004 ('ADTI Bill 2004')[361] in the House of Lords. The Bill would have enabled a competent adult who is suffering unbearably from a terminal illness to receive medical assistance to die at their own request. 'Medical assistance to die' referred to providing the patient with the means to end life, or ending that life if the patient is physically unable to do so.[362] The ADTI Bill 2004 included a requirement for the option of palliative care[363] to be discussed with patients before assisting their deaths.[364]

The ADTI Bill 2004 was given a Second Reading in March 2004. The Select Committee conducted an exhaustive examination of the Bill, including studies on public opinion and a comparison of the Bill to the laws of four jurisdictions (Switzerland, the Netherlands, Belgium, and Oregon(US))[365] where assisted death has already been legalised in some form.[366] The Select Committee published the 2004 HL Select Committee Report in April 2005 which presented the ethical and practical issues surrounding the Bill, and the arguments for and against a change in the English law.[367] Although the Select Committee failed to reach a consensus on the acceptability or

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[360] PAD Bill 2003 (n352).

[361] ADTI Bill 2004 (ch1 n48).

[362] ibid cl 1(2).

[363] See section 3.4.3.

[364] ADTI Bill 2004 (ch1 n48) cl 3(1).

[365] See ch 5.

[366] 2004 HL Select Committee Report Vol I (ch1 n49) paras2-7.

[367] 2004 HL Select Committee Report Vols I, II and III (ch1 n58).

otherwise of the ADTI Bill 2004, it did make recommendations for future legislation.[368] Some of the issues highlighted by the report were:

i) The ADTI Bill 2004 sought to legalise not only medical assistance with suicide but also, in cases where self-administration of lethal medication is not possible, voluntary euthanasia.[369] The Select Committee recommended that any future Bill should be clear in distinguishing between assisted suicide and voluntary euthanasia and to address these two courses of action separately, as the considerations involved in each are very different.[370]

   The Select Committee visited two jurisdictions with very different assisted death laws – Oregon, where only physician-assisted suicide is legal, and the Netherlands, where both physician-assisted suicide and euthanasia by physicians are legal. These showed very different annual rates of assisted deaths. The Select Committee found that whilst less than one in 700 deaths in Oregon was attributable to assisted death, that figure was more than one in 40 in the Netherlands. Of those deaths in the Netherlands, less than 10% were from assisted suicide, while over 90% were the result of euthanasia.[371] The Select Committee concluded that the inclusion of euthanasia in the law on assisted death had led to a significantly higher rate of assisted deaths. The Select Committee was also of the view that assisted suicide, with its emphasis on the individual taking responsibility for the final stage of ending their life, has the effect of making those who are minded to end their lives think more carefully before taking action to give effect to their wishes.[372]

   The Select Committee considered that any new Bill should be narrower in scope than the ADTI Bill 2004. It found that while some physicians supported a change in the law, the medical profession as a whole was at best ambivalent about legalising assisted death and in many cases opposed.[373] It considered that there would be less opposition to a law which was restricted to physician-assisted suicide. The Select Committee heard evidence from Oregon that any proposal to extend Oregon's Death

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[368] 2004 HL Select Committee Report Vol I (ch1 n49) para7.

[369] ADTI Bill 2004 (ch1 n48) cl 1(2). See also 2004 HL Select Committee Report Vol I (ch1 n49) para243. 'Voluntary euthanasia' is explained in ch1 n7.

[370] ibid para 246.

[371] ibid para 243.

[372] ibid para 244. See also section 3.3.4.

[373] ibid para 245.

with Dignity Act ('DDA')[374] to also legalise euthanasia was expected to encounter much greater opposition from the medical profession.[375] The Select Committee also noted that a blurring of the line between voluntary and involuntary assisted dying is more likely to occur by legalising voluntary euthanasia[376] than by legalising assisted suicide.[377] It emphasised a belief that the key issue with assisted death is that responsibility for the ultimate act should rest with the patient.[378]

It is submitted that the Select Committee's view that there would be less opposition from the medical profession for a law on assisted death that did not include euthanasia by physicians is no longer supported in England and Wales today. This is demonstrated by recent studies that found almost equal support for physician-assisted suicide and euthanasia by physicians in the UK. The first is Seale's 2007–2008 survey of doctors' attitudes (as referred to previously), that showed 35.2% of doctors surveyed supported physician-assisted suicide for the terminally ill, whilst 34% thought that doctors should be able to perform euthanasia for such patients.[379] The second study on doctors' attitudes was by McCormack et al in 2011. This study too found almost equal support for physician-assisted suicide and euthanasia but the level of support for both was lower than in Seale's earlier study. Whilst 24.9% of doctors were willing to perform physician-assisted suicide, 22.7% were willing to perform voluntary euthanasia.[380]

ii) 'Terminal illness' was defined by the ADTI Bill 2004 as an inevitably progressive illness which cannot be reversed by treatment, and which will likely result in death within a few months at most.[381] The Select Committee heard evidence that an accurate prognosis is not possible beyond 8–12 weeks.[382] The Royal College of Physicians ('RCP') gave evidence that prognosis of terminal illness was 'a probabilistic art' and that 'prognosticating may be better when somebody is within the last two or three weeks of their life' but that, 'when they are six or eight months

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[374] See section 5.7.2.

[375] 2004 HL Select Committee Report Vol I (ch1 n49) para245.

[376] 'Voluntary euthanasia' (ch1 n7).

[377] 2004 HL Select Committee Report Vol I (ch1 n49) para245. Although no support for this specific concern is found by this thesis in ch6.

[378] ibid para 246.

[379] Seale (n173).

[380] R McCormack et al, 'Attitudes of UK doctors towards euthanasia and physician-assisted suicide: a systematic literature review' (2012)26(1) Palliative Medicine 23.

[381] ADTI Bill 2004 (ch1 n48) cl 1(2).

[382] 2004 HL Select Committee Report Vols I, II and III (ch1 n58).

away from it, it is pretty desperately hopeless as an accurate factor'.[383] Similarly, the Royal College of General Practitioners stated that 'it is possible to make reasonably accurate prognoses of death within minutes, hours or a few days. When this stretches to months, then the scope for error can extend into years'.[384] These statements are supported by data from the Oregon Public Health Division's ('OPHD') annual reports, where some terminally ill people who had been given lethal drugs by physicians pursuant to the DDA, on the basis of a prognosis of six months or less had gone on to live longer, sometimes much longer, before either using the drugs to commit suicide or dying of natural causes.[385] The Select Committee recommended that, 'if a future [B]ill should include terminal illness as a qualifying condition, this should be defined in such a way as to reflect the realities of clinical practice as regards accurate prognosis'.[386]

iii) 'Unbearable suffering' was defined by the ADTI Bill 2004 as suffering, resulting from the patient's terminal illness, which the patient finds so severe as to be unacceptable.[387] The Select Committee heard evidence that suffering is a subjective experience, which cannot be assessed objectively by clinical methods, or reliably attributed to the underlying condition.[388] The Select Committee recommended changing the phrase 'unbearable suffering' to 'unrelievable suffering', to require that efforts be made to relieve any suffering, and restrict assisted dying to only those whose pain cannot be alleviated by palliative care.[389] Thus, a more objective medical assessment is made of the patient's suffering which ensures that all available steps have been taken to relieve distress.[390]

iv) The ADTI Bill 2004 provided that only if a physician believed that their patient is not competent, were they to refer the patient to a psychiatrist to confirm that the patient was not suffering from a psychiatric or psychological disorder causing impaired judgement.[391] However, the experience of Oregon's law on physician-assisted suicide was that referrals under similar provisions in the DDA were rare.[392]

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[383] 2004 HL Select Committee Report Vol I (ch1 n49) para118.

[384] ibid.

[385] OPHD, *Oregon's Death with Dignity Act: The Second Year's Experience* (Second Annual Report) 12; OPHD, *Sixth Annual Report on Oregon's Death with Dignity Act* 4. See section 5.7.2.

[386] 2004 HL Select Committee Report Vol I (ch1 n49) para269(c)(iii).

[387] ADTI Bill 2004 (ch1 n48) cl 1(2).

[388] 2004 HL Select Committee Report Vol I (ch1 n49) paras 127–130.

[389] J Keown, 'Debate Physician-Assisted Suicide: Lord Joffe's Slippery Bill' (2007)15 Med.L.Rev 126.

[390] ibid.

[391] ADTI Bill 2004 (ch1 n48) cl 8.

[392] 2004 HL Select Committee Report Vol I (ch1 n49) para153.

The Select Committee recommended that a patient requesting assisted dying should be given a psychiatric assessment by default, to confirm that the request is based on a reasoned decision free from external pressure, and that the applicant is not suffering from a psychiatric or psychological disorder causing impaired judgement.

v) The ADTI Bill 2004 required a specialist in palliative care to have discussed the option of palliative care with the patient.[393] However, the Select Committee stated that:

> if a future [B]ill is to claim with credibility that it is offering assistance with suicide…as complementary rather than alternative to palliative care, it should consider how patients seeking to end their lives might experience such care before taking a final decision.[394]

It recommended that patients should actually experience palliative care rather than merely be informed of such care as an option.[395] The Select Committee drew attention to evidence from a UK charity for hospice care, Help the Hospices, that 'experience of pain control is radically different from the promise of pain control, and cessation is almost unimaginable if symptom control has been poor'.[396] It concluded that patients seeking assistance to die without having experienced good symptom control could not be deemed fully informed.[397]

vi) The GMC gave evidence to the Select Committee that:

> A…law [on] physician-assisted dying would have profound implications for the role and responsibilities of doctors and their relationships with patients.[398] Acting with the primary intention to hasten a patient's death would be difficult to reconcile with the medical ethical principles of beneficence and non-maleficence.[399]

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[393] ADTI Bill 2004 (ch1 n48) cl 3(1).

[394] 2004 HL Select Committee Report Vol I (ch1 n49) para269(c)(vi).

[395] MA Branthwaite, 'Taking the Final Step: Changing the Law on Euthanasia and Physician Assisted Suicide' (2005) 331 BMJ 681.

[396] 2004 HL Select Committee Report Vol I (ch1 n49) para258.

[397] ibid.

[398] See section 3.3.3.

[399] Select Committee on the Assisted Dying for the Terminally Ill Bill, *Assisted Dying for the Terminally Ill Bill [HL] Vol II* (2004-05, HL 86-2) 11. See section 3.3.4 for 'beneficence' and 'non-maleficence'.

A similar observation was made by Finlay et al in their 2011 article on a reappraisal needed of safeguards for an assisted dying law. They argued that the underlying ethics of medicine is at variance with the ethics of assisted death, as the role of doctors is to treat illness or, where that is not possible, to relieve its symptoms and thereby improve quality of life.[400] The Select Committee considered that the issue was whether a reformed law on assisted dying should encompass 'therapeutic killing', or whether the therapeutic option of a physician giving a patient a lethal overdose crosses a 'Rubicon' that would radically alter the way every physician practices medicine.[401] With particular reference to implications for palliative care, Finlay argued in 2005, that once the option of a lethal overdose enters the arena, a paradigm shift occurs in medical decision-making. Assisted suicide and euthanasia become treatment options that would have to be presented to all terminally ill people who are believed to be in the last months of life.[402] This potential conflict between a physician's traditional role and responsibilities towards a patient, and physician-assisted death, was later emphasised in 2010 in the DPP's Policy which states that a factor in favour of prosecuting an assisted suicide is whether or not it is perpetrated by 'a medical doctor, nurse or other healthcare professional' and whether the deceased had been 'in his or her care'.[403]

2.4.3 *Assisted Dying for the Terminally Ill Bill 2005*

The House of Lords debated the 2004 HL Select Committee Report (discussed above) in October 2005.[404] Lord Joffe then introduced a revised Assisted Dying for the Terminally Ill Bill 2005 ('ADTI Bill 2005') in November 2005.[405] The purpose of the ADTI Bill 2005, which was modelled on Oregon's DDA,[406] was to 'enable an adult who has capacity and who is suffering unbearably as a result of a terminal illness to receive medical assistance to die at his own considered and persistent request'.

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[400] Professor Baroness Finlay and Lord Carlile QC, Living and Dying Well, *A Question of Public Safety, A fundamental reappraisal is needed of the concept of safeguards for 'assisted dying'* (2011). See section 3.3.7 on 'quality of life'.

[401] 2004 HL Select Committee Report Vols I, II and III (ch1 n58).

[402] IG Finlay et al, 'The House of Lords Select Committee on the Assisted Dying for the Terminally Ill Bill: Implications for Specialist Palliative Care' (2005)19 Palliative Medicine 444.

[403] DPP's Policy (ch1 n34) para 43(14).

[404] HL Deb 10 October 2005, vol 674, cols 12-32, 45-150.

[405] ADTI Bill 2005 (n354).

[406] See section 5.7.2.

The ADTI Bill 2005 did not permit euthanasia. However, whilst the Select Committee had recommended that a new Bill be limited to physician-assisted suicide, the ADTI Bill 2005 allowed not only for physicians to prescribe lethal medication to patients who request it, but to prescribe and provide a means of self-administration to patients for whom it would have been impossible to orally ingest medication.[407] As argued by Laurie, the ADTI Bill 2005 straddled the boundary between physician-assisted suicide and euthanasia as it would have permitted physicians to provide some assistance to patients who were physically unable to administer the lethal medication themselves.[408] The ADTI Bill 2005 did not adopt the Select Committee's recommendations for a patient to have actually experienced palliative care before being allowed the option of assisted dying, or for the term 'unbearable suffering' to be amended to 'unrelievable suffering'.[409] The ADTI Bill 2005 progressed to its Second Reading. However, the House of Lords voted against it in May 2006.[410]

2.4.4 *Coroners and Justice Bill 2009*

In May 2009, Lord Falconer campaigned for the legal protection from prosecution of individuals who assist their loved ones to travel abroad for an assisted suicide.[411] To this end, Lord Falconer proposed an amendment to the Coroners and Justice Bill 2009, which would have created an exception to the SA 1961. The proposed amendment would have effectively legalised aiding terminally ill people to travel abroad for an assisted suicide. It would have required the victim to make a declaration of their intention to die in writing, witnessed by an independent person.[412] Two physicians would have been required to be 'of the opinion in good faith' that the person was terminally ill and that they had the 'capacity to make the declaration of their intention to die'. The proposed amendment to the Coroners and Justice Bill 2009 was defeated in the House of Lords.[413]

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[407] ADTI Bill 2005 (n354) cl 1. R Gertz et al, 'Developments in medical law in the United Kingdom in 2005 and 2006' (2006)13(2) European Journal of Health Law 143.

[408] GT Laurie, 'Editorial, Physician Assisted Suicide in Europe: Some Lessons and Trends' (2005)12 Eur J Health L 5,7.

[409] HL Deb 12 May 2006, vol 681 col 1187-95.

[410] C Dyer, 'House of Lords rejects physician-assisted suicide' (2006)332 BMJ 1169.

[411] I Oakeshott, 'Lord Falconer Backs Suicide Reform' *Sunday Times* (London,31 May 2009).

[412] HL Deb 7 July 2009, vol 712, cols 595-98.

[413] ibid col 634.

2.4.5 *Commission on Assisted Dying 2010*

The Commission on Assisted Dying was a non-governmental and non-parliamentary group which was established in September 2010. It was an independent body commissioned by two private individuals who had previously spoken in support of assisted suicide – author Terry Pratchett and businessman Bernard Lewis.[414] The purpose of the Commission was to investigate what system, if any, should exist to allow people to be assisted to die and whether it might be possible to introduce sufficient safeguards within such a system to prevent abuse and ensure that vulnerable people[415] could not be pressured to choose an assisted death. The Commission considered the impact that a regulatory regime for assisted dying might have on individual people and society more broadly.

The Commission consulted with a wide range of stakeholders to examine their views on these issues. Its inquiry into 'assisted dying' included a public call for evidence, public evidence hearings, international research visits to four jurisdictions, original research and commissioned research. Its original research concerned the relationship between suicide and serious physical illness, and also attitudes on assisted dying among people from 'vulnerable groups'. Its commissioned research concerned the effectiveness of legal safeguards, and the quality of palliative care,[416] in jurisdictions that permit some form of assisted dying.[417]

In its January 2012 Report, the Commission concluded that it is possible to formulate a legal framework with strictly defined circumstances in which terminally ill people could be assisted to die, while providing upfront safeguards to protect potentially vulnerable people.[418] The Commission's Report drew attention to some of the more significant considerations for a permissible assisted death. These include i) a good level of care and support services for the terminally ill with properly trained health and social care staff, ii) clearly defined eligibility criteria, iii) the patient has the capacity to make a request for assisted death, iv) the physician knows the person well, v) the patient is fully informed of all the options available for treatment, care and support, vi) an assessment

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[414] See ch1 n50.

[415] See section 3.4.6.

[416] See section 3.4.3.

[417] APPG, 'Bill consultation: Latest news' (ch1 n56). See also *Report of the Commission on Assisted Dying* (ch1 n51).

[418] *Report of the Commission on Assisted Dying* (ch1 n51).

by at least two physicians who are wholly independent of one another, vii) guidance on how lethal medication is to be used, stored, transported and administered to avoid risk of abuse viii) the patient must carry out the final act that will end their own life, ix) the death is certified and recorded as an assisted death, and x) the assisted death is reported to a national monitoring commission that reviews all cases and has retrospective powers to investigate compliance with the law.[419]

The Commission recommended that a person requesting an assisted death should satisfy the following four criteria: i) be aged 18 or over, ii) have a diagnosis of terminal illness, iii) be making a voluntary choice that is an expression of their own wishes and is not unduly influenced by others, and iv) have the mental capacity to make a voluntary and informed choice, with their decision-making ability unimpaired as a result of mental health problems such as depression.[420] To protect the vulnerable in society and avoid any potential abuse, the Commission proposed firstly, a decision-making model involving the assessment, advice, support and independent judgements of two independent doctors, with support from other health and social care professionals where necessary, secondly, safeguards to ensure (i) that the patient has been fully informed of all other treatment and end of life care options that are available and still wishes to proceed (ii) that the eligibility criteria are met (iii) that the patient has a settled intention to die (iv) the safe storage and transportation of any lethal medication (v) that the patient has a reliable and supported assisted death (vi) that assisted deaths are reported correctly, and thirdly, monitoring and regulatory oversight by a national monitoring commission with powers to investigate suspected non-compliance.[421]

It is contended that the independence of the Commission is to be questioned. The Commission was set up with funding provided by two assisted suicide supporters (discussed above).[422] The 'think-tank' organisation, Demos, that provided the research secretariat and administrative support to the Commission, responded to a tender from these two individuals.[423] The British pro-assisted suicide lobby group, Dignity in Dying brokered the relationship between Demos and these individuals.[424] As such, the validity or strength of the results of the Commission's inquiry is debatable. Further, it is not

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[419] ibid 301.

[420] ibid 301.

[421] ibid 302.

[422] See further 'About the Commission on Assisted Dying' (ch1 n50).

[423] ibid.

[424] ibid.

known how the selection procedures for the public call for evidence and public hearings were conducted. Thus, it is doubtful if the findings of the Commission are reflective of an objective, and independent gathering of evidence, and evaluation of results.

2.4.6 *Assisted Dying Bill 2013*

In 2013, Lord Falconer introduced a Private Member's Bill, the Assisted Dying Bill 2013 ('AD Bill 2013'), into the House of Lords. It received its First Reading on 15 May 2013.[425] A date has not yet been set for the Bill's Second Reading. The AD Bill 2013, which is based on the findings of the Commission's 2012 Report, seeks to license doctors to provide mentally competent patients who are terminally ill with less than six months to live with the means to end their lives – i.e. physician-assisted suicide.[426] Under the AD Bill 2013, a patient would have to prove that they have (i) the mental capacity to make a voluntary and informed choice, (ii) are not being unduly influenced by others and (iii) have a 'settled intention' about their wish to die.[427] Two doctors would have to independently assess the patient to confirm that the patient has a terminal illness with a prognosis of six months or less to live.[428] The patient would also have to be informed of the palliative, hospice, and other care which is available.[429] The patient would have to wait for at least 14 days before the prescribed lethal medication is delivered (by the attending doctor, a registered medical practitioner or a registered nurse) to him or her.[430] In cases where a patient is expected to die within one month, the waiting period may be reduced to six days.[431]

Other important features in the AD Bill 2013 include, an assisting health professional to (i) prepare the medicine for self-administration, or to prepare a medical device which will enable the person to self-administer the medicine, and to assist the person to ingest or otherwise self-administer the medicine, and (ii) remain with the person until the person has self-administered the medicine and died, or decided not to self-administer the medicine.[432]

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[425] AD Bill 2013 (ch1 n57).

[426] ibid cl 2.

[427] ibid cl 3.

[428] ibid cl 3.

[429] ibid cl 3.

[430] ibid cl 4.

[431] ibid cl 4.

[432] ibid cl 4.

Some noteworthy concerns with the AD Bill 2013 are discussed below and will be considered again in Chapter Seven in the context of the reform agenda for England and Wales.

i) The AD Bill 2013 does not specify how a physician should confirm that a patient has the required mental capacity to make a voluntary, informed and settled decision to die.[433] There is no requirement in the Bill for a mental health evaluation, even in cases where the assessing doctor has doubts about the patient's mental capacity or suspects that the patient's judgement is impaired by depression.[434] Thus, there is potential for abuse under this Bill. As clinical depression may be undetected or overlooked, vulnerable patients may be at risk under this Bill.

ii) The AD Bill 2013 seeks to offer assisted suicide to terminally ill people with a prognosis of six months or less to live.[435] In this regard, the findings and recommendations of the 2004 HL Select Committee Report have been disregarded.[436] As discussed above, the Select Committee heard evidence that accurate prognosis is not possible beyond a few weeks.[437] It was informed that a prognosis of terminal illness that stretches to months would be unreliable.[438] Nevertheless, reliance on the prognoses available under current medical technology may be an unavoidable limitation.

iii) A majority of physicians in England and Wales oppose the legalisation of physician-assisted suicide. This is demonstrated by Seale's 2007-2008 survey (discussed above) which found that only 35.2% of doctors surveyed supported physician-assisted suicide for the terminally ill.[439] The lack of support by English physicians for a law on physician-assisted suicide may encourage 'physician shopping' under the AD Bill 2013.[440] As explained by Butler-Sloss et al, physicians who support the legalisation of assisted death may be more 'willing' to make favourable assessments and write prescriptions for lethal medication for patients whose regular physicians are unwilling to do so under the Bill.[441] However, a physician who has only recently

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[433] Butler-Sloss et al, Living and Dying Well, '*Another "Assisted Dying" Bill: Does It Pass The Public Safety Test?: An Analysis of the Assisted Dying Bill [HL Bill 24]* para6 (20 June 2013).

[434] ibid para14.

[435] AD Bill 2013 (ch1 n57) cl 2(1)(b).

[436] Butler-Sloss (n433) para 9.

[437] 2004 HL Select Committee Report Vol I (ch1 n49) para 118.

[438] See text to nn382-386.

[439] Seale (n173).

[440] Butler-Sloss (n433) para 13.

[441] ibid para 11.

been introduced to a patient may not be able to make an assessment of the latter's mental state or whether factors in their personal or family life are unduly influencing their request for assisted suicide.[442] As will be discussed in Chapter Five, physician-shopping is a common practice under the DDA in Oregon.

iv) The AD Bill 2013 allows for a 14-day 'cooling off' period before the prescribed lethal medication is delivered to the patient, with a shorter period of just six days where death is expected within one month.[443] Camden-Smith argues that such short 'cooling off' periods may not offer adequate time for a patient to reconsider and reflect on their decision.[444] Nevertheless, as recommended by the Select Committee, the Bill balances the need to avoid increased suffering for determined applicants against the desirability of providing time for reflection for the less resolute.[445]

v) Under the AD Bill 2013, a request for assisted suicide would not necessarily be acted on as soon as the 'cooling off' period has expired. The lethal medication would only be supplied to the patient if and when requested by the patient after that period. However, as observed by Camden-Smith, given the progressive nature of terminal illness, mental capacity may be lost in the period between the request being approved and the drugs being supplied and swallowed.[446] As she clearly points out, the relationship between time and capacity is explicitly laid out in the MCA 2005. It states that 'an assessment of a person's capacity must be based on their ability to make a specific decision at the time it needs to be made'.[447] Thus, Camden-Smith's argument that, an assessment of capacity made at one point in time cannot be regarded as valid for a decision taken at a subsequent point, which may be weeks or even months later, is compelling.[448]

The proposals for law reform discussed above will be referred to and examined further in the proceeding chapters, particularly in Chapter Seven on the recommended law reform for England and Wales.

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[442] ibid para 11.

[443] AD Bill 2013 (ch1 n57) cl 4.

[444] C Camden-Smith, Living and Dying Well, *Mental Capacity and Assisted Suicide – To what extent can mental capacity be reliably assessed in patients seeking physician-assisted suicide?* (16 July 2013).

[445] 2004 HL Select Committee Report Vol I (ch1 n49) para269.

[446] Camden-Smith (n444) para26.

[447] MCA 2005, Code of Practice, para4.4.

[448] Camden-Smith (n444) para26.

2.5 Conclusion

This chapter analysed the current law on assisted death in England and Wales. Under this law, euthanasia is prohibited by the law of murder and manslaughter. Whilst assisted suicide is also a crime, any prosecution for this offence requires the consent of the DPP. From the analysis undertaken, the chapter concludes that the law is unsatisfactory, and that it fails to meet the needs of society in general, or of those seeking an assisted death. The reasons for these conclusions are as follows.

The chapter established that the current English law on assisted suicide in England and Wales is incoherent. Firstly, by decriminalising suicide, English law has recognised an individual's autonomous right to end their own life. However, by maintaining assisted suicide as a crime, sanctity of life and protection of the vulnerable have taken precedence over autonomy, for those suicides which involve the assistance of others. The incoherence of this inconsistency is demonstrated by the preponderance of assisted suicide cases that have not been regarded as culpable by the DPP (i.e. where the DPP has deemed prosecution not to be in the public interest).

Secondly, English law is increasingly inconsistent between its approach to end-of-life medical decisions and its approach to assisted death. The chapter demonstrated this inconsistency in the case of *Re B*, where English law did not recognise a competent patient's right to die with assistance, but did allow Ms B to achieve death by exercising her right to refuse life-sustaining treatment. It is morally indefensible that patients such as Ms B must end their lives by refusing life-sustaining treatment and die a potentially prolonged and painful death, and that they are prevented from ending their lives more directly and humanely through the ingestion of lethal medication.

Thirdly, by upholding the doctrine of 'double effect' whilst maintaining euthanasia as a crime, English law incoherently relies upon the physician's intention as the distinguishing feature between these two. Under English law, a physician is permitted to administer a patient with palliative medication, with the intention of relieving pain and discomfort, even if it foreseen that the patient's death will be hastened as a result of such a high dosage of medication. However, the administration of excessive palliative medication crosses the line to become an illegal act which precipitates death.[449] Although it is a physician's intention which determines whether they may rely upon the doctrine of double effect as a defence, the law fails to cohesively address situations where a physician has not only an intention to relieve suffering, but also an intention to hasten death.

Fourthly, by allowing life-sustaining treatment to be withdrawn from incompetent patients in their 'best interests' whilst maintaining euthanasia as a crime, English law is further incoherent in its reliance upon a distinction between an 'omission' and an 'act'. This was demonstrated in Bland's case, where life-sustaining treatment was permitted to be withdrawn from an incompetent patient in Bland's 'best interests', as the treatment was determined to be futile and burdensome. The House of Lords held that the withdrawal of treatment was an 'omission' to treat, rather than an 'act' causing death.

As cogently argued by Sayers, the danger of re-describing indirect euthanasia and non-voluntary euthanasia[450] in medical terms such as the 'doctrine of double effect' or 'acts' versus 'omissions' is that physicians may thereby either wittingly or unwittingly practice euthanasia with no oversight.[451]

The chapter also considered the DPP's Policy, including the public interest factors taken into account when deciding whether to prosecute an assisted suicide. Several difficulties were demonstrated in respect of the policy's application. Firstly, there is difficulty in retrospectively establishing a suspect's motives after a victim's death. Yet, under the policy, compassion is the key determining factor which will place a criminal act beyond the reach of the criminal courts.[452] In this regard, society's need to protect the vulnerable is not well met.

Secondly, the DPP's Policy is unclear as to what actions would amount to 'minor encouragement or assistance', and which would thus be less likely to be prosecuted. Thirdly, the Policy is unsatisfactory for discouraging those wanting an assisted suicide

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[449] R Magnusson, 'The Sanctity of Life and The Right to Die: Social and Jurisprudential Aspects of The Euthanasia Debate in Australia and The United States' (1997)6 Pac.Rim L.& Pol'y J 1,79.

[450] 'Non-voluntary euthanasia' (text to ch1 n98).

[451] GM Sayers, 'Non-Voluntary Passive Euthanasia: The Social Consequences of Euphemisms' (2007)14 Eur J Health L. 221,225.

[452] A Mullock, 'Prosecutors making (bad) law?' (2009)17 Med.L.Rev 209.

from accessing medical expertise.[453] This was noted by the Court of Appeal in *Nicklinson* when they requested that the DPP's Policy be amended to provide more clarity for healthcare professionals as to permissible assistance. As was asserted in the chapter, although the majority of healthcare professionals in England and Wales are opposed to the legalisation of physician-assisted suicide, only they have the required expertise to provide a safe and humane assisted death.

As the DPP's Policy does not meet the needs of those seeking an assisted suicide, it encourages those who can travel to right-to-die organisations abroad to do so while they still can, even if they would prefer to wait. If such 'suicide tourism' is infeasible for a patient due to financial or health reasons, then the burden of assisting their suicide will most probably fall on someone with no experience and no access to expert information.[454] As noted by Seale, '[B]otched suicides assisted by amateurs and ill-considered decisions to die by some of the most vulnerable people in society are the likely outcomes of the [DPP's Policy]'.[455]

What adds to the uncertainty of the DPP's Policy, is that it neither decriminalises assisted suicide nor provides assurances of immunity. Yet there have been no prosecutions for assisted suicide since the Policy was published. Further, the DPP also has the ability to change the DPP's Policy with no consultation. In these two aspects — the uncertainty of the policy and the discrimination against those who are unable to travel — the DPP's Policy further fails to meet the needs of those seeking an assisted death.

Two significant statistics were discussed in this chapter, both indicating that the needs of those seeking an assisted death are not being met. Firstly, public opinion polls. These included the 2010 YouGov poll for the *Daily Telegraph* newspaper, which found that 82% of respondents wanted a change in the law.[456] Secondly, the surveys by Seale on the incidence of unlawful deaths facilitated by healthcare professionals as part of end-of-life medical practice.

Recent attempts at legislative reform in England and Wales have also been highlighted in this chapter. They are an acknowledgement by many, that the current law is

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[453] Lewis (n151).

[454] Lewis (n97) 130.

[455] Seale (ch1 n20).

[456] 'YouGov / Daily Telegraph Survey Results, 26th - 28th January 2010' (n193).

unsatisfactory. As a means of protecting the vulnerable, these attempted reforms have focused on providing the option of physician-assisted suicide to terminally ill patients. Other potential safeguards were also highlighted in this chapter — such as requirements for mental capacity, unbearable suffering, and palliative care. These will be considered in more detail in Chapters Three, Five and Seven. The following chapter, Chapter Three, will consider the social and ethical context of the current law on assisted death in England and Wales.

Chapter 3: The Social and Ethical Context of the Law on Assisted Death

3.1 Introduction

Following the discussion of the scope of the current law on assisted death[1] in England and Wales in the previous chapter, this chapter will examine the social and ethical influences affecting the development of this law. It will compare traditional influences with those that are shaping debate on assisted death today, and discuss the interrelationships between these influences. The chapter will demonstrate that English law does not wholly meet society's needs and is inconsistent and morally indefensible.

The social influences that will be examined are religion, a rise in individualism, and an ageing population. The ethical influences that will be explored are the sanctity of life, a right to self-determination, professional ethics, the doctrine of double effect, the concept of 'quality of life', paternalism, and an increasing scarcity of healthcare resources. Frameworks for such ethical influences will also be considered in the chapter. These include the traditional Hippocratic Oath previously sworn by physicians and the 'four-principle' model of medical ethics (i.e. respect for autonomy, non-maleficence, beneficence and justice in medical care) developed by Beauchamp and Childress.[2] The two main ethical measures for assessing the morality of actions — consequentialism and deontology — will also be discussed. Other factors having an effect on the present debate on assisted death will also be examined. These include public trust in physicians, advances in medical technology, effective and adequate palliative care, concerns over loss of dignity, the 'slippery slope' argument, protecting vulnerable members of society, the laws on assisted death of other jurisdictions, and the role of the media. The chapter will examine the impact of these influences on both the law of assisted death, and on the legally permitted end-of-life medical decisions which were discussed in the previous chapter.

Most of the influences examined in this chapter in relation to England and Wales have also impacted the other jurisdictions considered in Chapter Five that have legalised

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[1] 'Assisted death', defined in section 1.1.

[2] TL Beauchamp and JF Childress, *Principles of Biomedical Ethics* (6th edn, OUP 2008).

assisted death in some form – the Netherlands, Belgium, Northern Territory (Australia), and the State of Oregon (US).

3.2 Social influences

3.2.1 *Religion*

Christian culture has traditionally been a key influence in England and Wales on the law and public policy governing both assisted death and end-of-life medical decisions. A report on the 2009-10 Citizenship Survey showed that 79% of UK citizens affiliated themselves to a religion.[3] Although the Christian faith (70%) was the most prevalent religion, the proportion of Christian citizens had fallen from 77% in 2005. Other religions were much less prevalent (4% Muslim, 2% Hindu, 1% Sikh and 2% other). Further evidence that the predominance of the Christian faith is declining in the UK, is provided in the *26th Report of the BSA 2010 survey* (‘*26th BSA Report*’).[4] According to the *26th BSA Report*, 66% of UK citizens in 1983 identified themselves as being Christian, declining to 50% in 2008, and then 43% in 2009. The *28th BSA Report* showed that this figure has remained at 44% in 2011.[5] The *26th BSA Report* also noted that the proportion identifying themselves as belonging to a non-Christian religion has conversely risen from 2% in 1983, to 5% in 2009. The *28th BSA Report* then showed a further rise to 6% in 2011. Whilst this thesis is focused on England and Wales, the *BSA* figures referred to here are for the entire UK.

As observed by Engelhardt, Christianity upholds the sanctity of life, and regards suicide as self-murder, and thus assisted suicide and euthanasia as forms of assisted self-murder. Although Christianity imposes no religious obligation to postpone death or prolong life with life-sustaining treatment, a patient may have a religious duty to use medical technology to gain a last opportunity for repentance.[6]

It is argued that, in recent times, two trends have characterised the influence of religion in England and Wales. The first is a trend towards pluralism. England, today, is a culturally pluralistic society which maintains that no person should be bound by the

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[3] Department of Communities and Local Government, *Race, Religion and Equalities: A report on the 2009-10 Citizenship Survey* (21 December 2011).

[4] McAndrew (ch1 n70).

[5] A Park et al (eds), NatCen Social Research, *BSA: the 28th Report* (Sage,2012). As noted by the report, the largest decline has been in affiliation with the Church of England, which has halved since 1983 (from 40% to 20%).

[6] HT Engelhardt and AS Iltis, ‘End-of-life: the traditional Christian view’ (2005)366 Lancet 1045.

dictates of another’s religion. This pluralism compels a consideration of the views of non-Christian religions towards assisted death and end-of-life medical decisions. For Islam, as a non-Christian example, the sanctity of life is ordained in the *Quran*: ‘Do not take life which God has made sacred except in the course of Justice’ (6:151). Islam maintains that life-sustaining treatment should not be withheld or withdrawn unless death is inevitable.[7] In Hinduism, there has been a tradition of ‘religious suicide’. Such ‘self-willed’ deaths, according to Firth, have been ‘linked to a specific purpose: to obtain freedom through an act of omnipotence involving the sacrifice of the self’. As Hinduism views suffering as ‘purifying’ and ‘cleansing’, it regards the suicide of a person wishing to end intolerable pain and suffering as morally wrong.[8] Hindu religious tenets are generally opposed to the withholding and withdrawal of life-sustaining treatment from incompetent patients, because such decision-making does not reflect the patient’s autonomous decision and therefore can be abused.[9]

Sikhism, which derives its ethics from the teachings of Guru Granth Sahib and its code of conduct, the *Rehat Maryada*, considers life as a gift from God.[10] Sikhism is not in favour of assisted death as it holds that the timing of birth and death is in God’s hands, and that suffering is part of karma.[11] Judaism’s position on end-of-life is that one’s body belongs to God.[12] Therefore, as noted by Dorff, one does not have the right to commit suicide, and anyone who assists with a suicide commits murder. Judaism restricts the withholding or withdrawal of life-sustaining treatment to situations where there is certainty that the patient will die within 72 hours.[13] Buddhism generally rejects assisted death, as it is contrary to its First Precept, which prohibits intentional killing.[14] In Buddhism, the withdrawal of life-sustaining treatment from patients in a PVS would be a denial of ‘universal compassion’, which is a core facet of Buddhism.[15]

Although pluralism means that non-Christian religions now represent a significant proportion of English society, as noted above most of the religions which are significant

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[7] A Sachedina, ‘End-of-life: The Islamic View’ (2005)366 Lancet 774.

[8] SH Firth, ‘End-of-life: A Hindu View’ (2005)366 Lancet 682.

[9] ibid.

[10] ‘Sikhism: Ethics: Euthanasia, assisted dying, and suicide’ (*BBC*,27 October 2009) <www.bbc.co.uk/religion/religions/sikhism/sikhethics/euthanasia.shtml> accessed 9 March 2013.

[11] ibid.

[12] EN Dorff, ‘End-of-life: Jewish perspectives’ (2005)366 Lancet 862.

[13] ibid.

[14] D Keown, ‘End-of-life: The Buddhist View’ (2005)366 Lancet 952.

[15] ibid.

in the UK share with Christianity a belief in the sanctity of life. Therefore, the trend towards pluralism will have little impact on the proportion of society who regards the current law on assisted death as acceptable.

The second trend which characterises the influence of religion in England and Wales is a shift towards being a more secular society. A useful definition of secularisation is provided by Berger, who describes it as, 'the process by which sectors of society and culture are removed from the domination of religious institutions and symbols'.[16] Berger's description includes 'the secularisation of consciousness', of which he says 'that the modern West has produced an increasing number of individuals who look upon the world and their own lives without the benefit of religious interpretations'.[17] This suggests that the trend towards secularisation means that the ideology of any religious faith may be less influential on English law today than it was previously.

Support for this trend towards secularisation in England and Wales is demonstrated in the findings of the recent *BSA* surveys. According to the *26th* and *27th BSA Reports*,[18] the percentage of Britons who profess no religion rose from 31% in 1983 to 43% in 2008, with a further rise to 51%, in 2009-2010. The *28th BSA Report* showed that the figure remained at 50% in 2011. In summary – one in three (31%) in 1983 did not belong to a religion, compared with one in two (50%) in 2011.[19] However, the *29th BSA Report* in 2012 showed that the percentage of Britons with no religion then dropped to 45.7%.[20] The *26th* and *27th BSA Reports* further found that only 37% of all people with a religious 'affiliation' saw themselves as actively practising their religion. Thus, those with a religious affiliation are tending to be 'less religious'. However, this percentage varied by religion.[21]

It is submitted that the decline in religious affiliation in England and Wales is primarily brought about by generational replacement, with older, more religious, generations dying out and being replaced by less religious generations.[22] This is demonstrated by the

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[16] P Berger, *The sacred canopy* (Doubleday 1967).

[17] ibid.

[18] McAndrew (ch1 n70); A Park et al (eds), NatCen Social Research, *BSA: the 27th Report* (Sage,2011).

[19] L Lee, '[Chapter] 12. Religion: Losing Faith?' in *BSA: the 28th Report* (n5) 181.

[20] A Park et al (eds), NatCen Social Research, *BSA: the 29th Report* (2012).

[21] Whilst the majority of people identified themselves as Christian, those that did so were notably less likely than all other main religions to be actively practising their religion. Only 33% of Christians actively practised their religion, compared with 79% of Muslims, 74% of Sikhs and 70% of Hindus.

[22] Lee (n19) 181.

findings in the *28th BSA Report*.[23] In 1983, 55% of those born between 1956 and 1965 (then aged 18–27) did not belong to a religion, compared with 12% of those born before 1915 (then aged 68+). By 2010, 65% of the youngest generation (born between 1986 and 1992 and then aged 18–24) did not belong to a religion, compared with 24% of the oldest generation (born between 1926 and 1935 and then aged 75+). In 2011, nearly two thirds (64%) of those aged 18–24 did not belong to a religion, compared with 28% of those aged 65 and above.

This suggests that the trend towards secularisation in England and Wales will continue. Each generation is less likely than its predecessor to be born into religious families, and this lack of religiosity will tend to remain with an individual as they get older.[24] It is argued that there will be a continued increase in liberal attitudes towards assisted death, as the influence of considerations grounded in religion declines.[25] As such, the overall religious attitudes of society can no longer be relied upon to justify the current prohibition on assisted death. Further, according to the *26th BSA Report*, in 2009, 71% of those with faith, and 92% of those without, believed that a physician should be allowed to end the life of a patient with an incurable disease.[26] It is thus argued that for both those with faith, and those without, the sanctity of life ethic is no longer regarded as absolute. As such, religion itself is not as much of an influence on the debate on the legalisation of assisted death as it might have once been.

3.2.2 *Rise in individualism*

A trend towards individualism in modern Western culture, including England and Wales, is a social influence which has encouraged support for personal autonomy and self-determination, and thus the right to choose the manner, time, and place of one's own death.[27] As a result, there have been numerous attempts at law reform in England and Wales, and debate on the legalisation of assisted death is as rife as ever. Smith argues that individualism is based on an idea that:

> we each own our own body and hence should be able to do what we choose with our physical self — including destroy it. Not only that, but if we want

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[23] ibid 181.

[24] ibid 182.

[25] ibid 182.

[26] McAndrew (ch1 n70).

[27] MA Somerville, 'Against Euthanasia' (2006)5(4) Arts and Opinion.

> to die, liberty dictates that we should have ready access to a 'good death', a demise that is peaceful and pain-free.[28]

As observed by Somerville, Western countries today are placing more emphasis on the 'individual' than on society as a whole:

> We are now societies based on intense individualism possibly individualism to the exclusion of any real sense of community, including in situations facing death … Matters such as euthanasia, that would have been largely the subject of moral or religious discourse are now explored in our courts and legislatures, particularly through the concepts of individual human rights.[29]

Somerville argues that by permitting an autonomous choice for an assisted death, this would 'damage important, foundational societal values and symbols that uphold respect for human life'.[30]

It is submitted that while as a society we should be concerned about the rights of the individual, we must also be concerned about the rights of society as a whole and the protection of its rights. The interests of family and the various sectors of society must be balanced against patient autonomy and individual choice.

3.2.3 *Ageing population*

A factor which has shaped the social debate on assisted death in England and Wales has been the rapid growth in the proportion of elderly people (defined as over-65s) in society. Support for a law on assisted suicide in the UK from the older generations is demonstrated in the results of the July 2009 Populus poll for *The Times* newspaper. The results of the survey showed that among the older respondents who favoured the legalisation of assisted suicide in certain circumstances, 89% of those between 55 and 64 years, and 90% of those aged 65 and over ('65+'), felt that assisted suicide should be legalised for people with terminal illness.[31] In their 1995 study on euthanasia and the role of good care, Seale and Addington-Hall found that the loss of independence is an important aspect of quality of life that influences the desire for assisted death in the

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[28] WJ Smith, 'Euthanasia advocates work to make suicide easy' *National Review* (New York,15 November 2004).

[29] MA Somerville, 'Legalising Euthanasia: Why Now?' (1996) 68(3) Australian Quarterly 1,5.

[30] MA Somerville, 'The Case against Euthanasia and Physician-Assisted Suicide' (2003)(Spring) Free Enquiry 33.

[31] 'The Times Poll: July 17th-19th 2009' (ch1 n62).

elderly.[32] In an earlier 1994 study on why people want to die earlier, they found that an increasing population of elderly people with associated disabilities and distress, and the role played by modern medical technology in preserving life, have both fuelled public moral concerns about the merits of assisted death.[33]

The growth and age composition of the ageing population in the UK, along with associated health concerns will be considered here. In 2010, there were 10.3 million people aged 65+ in the UK.[34] According to the Office for National Statistics,[35] this number is projected to increase by 23%, to 12.7 million in 2018.[36] Growth in this age group is projected to continue for the foreseeable future, with the 65+ population expected to reach 16.9 million by 2035.[37] Irving's 2011 study similarly estimated that by 2040, there will be 15 million people in the UK aged 65+.[38] There has also been a substantial change in the age composition of older people. In 1951, those aged 85 and over ('85+') made up just 4% of the 65+ population. In 2010, this figure had increased to 14%.[39] According to the Office for National Statistics, the very old are the fastest growing group in the UK. In 2012, there were 1.4 million people aged 85+.[40] This is projected to increase to 2.0 million by 2022 and to 3.6 million by 2037, more than doubling over 25 years.[41] The ageing population in England and Wales has increased the proportion of society living in poor health or with disabilities. In 2010, the expected years lived in poor health from age 65 onwards was 7.7 years for men and 8.7 years for women,[42] whilst the expected years lived with disabilities was 8 years for men and 9 years for women.[43] Further, life expectancy at birth in the UK is projected to rise from

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[32] C Seale and J Addington-Hall, 'Euthanasia: the role of good care' (1995)40(5) Soc Sci Med 581.

[33] C Seale and J Addington-Hall, 'Euthanasia: Why People Want to Die Earlier' (1994)39(5) Soc Sci Med 647,652.

[34] T Rutherford, *Population ageing: statistics* SN/SG/3228 (House of Commons Library,10 February 2012).

[35] Rutherford (ibid) was based on the Office for National Statistics, National Population Projections, 2010-Based Statistical Bulletin (26 October 2011).

[36] Rutherford (n34).

[37] ibid.

[38] E Irving, 'The United Kingdom's Ageing Population: UK Population Growth Slows Down as Population Ages' (*About*,6 February 2011) <http://geography.about.com/od/populationgeography/a/The-United-Kingdoms-Ageing-Population.htm> accessed 6 February 2013.

[39] Rutherford (n34).

[40] Office for National Statistics, *National Population Projections, 2012-Based Statistical Bulletin* (6 November 2012).

[41] ibid.

[42] Rutherford (n34).

[43] Office for National Statistics, *Health expectancies at birth and at age 65 in the United Kingdom, 2008-10* (29 August 2012).

78.5 years in 2010 to 83.3 years in 2035 for men; and from 82.6 years in 2010 to 87.0 years in 2033 for women.[44]

Cracknell notes that the ageing population of the UK is partly a consequence of the large number of people born immediately after the Second World War and during the 1960s 'Baby Boom'.[45] He notes that it also stems from increased life expectancy, due to advances in medical technology. These trends put increasing demands on healthcare resources, as noted in section 3.3.9. The over-65s already represent the largest cohort of patients in the NHS. They account for over 75% of NHS patients, 60% of hospital admissions, and 70% of bed days in NHS hospitals. 39% of over-65s are estimated to have a limiting longstanding illness.[46]

3.3 Ethical influences

3.3.1 *Sanctity of life*

The current prohibition on assisted death upholds the doctrine of 'sanctity of life', i.e. that life should be respected. The doctrine has its roots in Judeo-Christian traditions, which emphasise the intrinsic worth and equal value of human life.[47] Pursuant to such religious traditions, human life is created in the image of God and therefore possesses an intrinsic dignity.[48] Nevertheless, Fitzpatrick forcefully argues that a religious basis for sanctity of life works only for those who share the same religious view.[49] As such, a prohibition on assisted death derived from a religious belief should not apply to those who do not share that religious belief.[50] However, Keown argues that even without a religious basis, one's 'right to life' is essentially a right not to be intentionally killed.[51] Glover too defines sanctity of life as 'an absolute barrier, an absolute ban, not derived from a religious source on the intentional taking of innocent human life'.[52] As discussed in section 3.2.1, given the trend towards a more secular society in England and Wales,

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[44] Rutherford (n34).

[45] R Cracknell, *The ageing population: The UK's ageing population has considerable consequences for public services* (House of Commons Library Research, 2010).

[46] Office for National Statistics, *General Lifestyle Survey, 2008 Report*.

[47] J Keown, 'Restoring Moral and Intellectual Shape to the Law after Bland' (1997)113 LQR 481.

[48] ibid.

[49] F Fitzpatrick, *Ethics in Nursing Practice* (Linacre Centre 1988) 185–202.

[50] RF Weir, *Ethical Issues in Death and Dying* (Columbia University Press 1977) 300.

[51] Keown (n47).

[52] Professor Jonathan Glover's definition of sanctity of life formed part of his submission to the Select Committee on the ADTI Bill 2004: 2004 HL Select Committee Report, Vol I (ch1 n49) para 53.

and the fact that sanctity of life is no longer regarded as absolute by those with and without faith, there is less reliance on 'sanctity of life' arguments by those opposing the legalisation of assisted death.

Sanctity of life arguments alone cannot coherently be the rationale for the current prohibition on assisted death in England and Wales, as neither legally permitted end-of-life medical decisions,[53] nor the law decriminalising suicide,[54] conform to the doctrine of sanctity of life. McGee, however, maintains that the doctrine of sanctity of life remains intact in legally permitted end-of-life medical decisions concerning the withdrawal and withholding of life-sustaining treatment. The doctrine of sanctity of life according to McGee, is not about preserving life at all costs, but about 'not taking control of death'.[55] He argues that human intervention into the natural sequence of events occurs at the stage of administering treatment. When life-sustaining treatment is withdrawn or withheld, physicians are allowing nature to finally take its course and the patient to die naturally from the condition that has afflicted them.[56] Conversely, McGee argues that assisted death involves taking control of one's death, as nature is overridden by bringing about the patient's death before its time. It is argued here, however, that the death that a patient is likely to experience when life-sustaining treatment is withdrawn is not a natural one (e.g. starvation). Whilst life-sustaining treatment may change a patient's death from its natural course, an assisted death (e.g. a lethal injection) may bring a patient's death closer to what it would have naturally been, had there never been the invasive intervention of medical treatment.[57]

Harris justifies the withdrawal and withholding of life-sustaining treatment from an incompetent patient in a PVS (as in Bland's case),[58] by qualifying the 'sanctity of life' with a distinction between 'life' and mere 'existence'. He argues that if there is no probability of a person ever regaining consciousness, then they have no ability to value their own existence, and have thus ceased to be a person.[59] Accordingly, the provision of ANH to such patients in a PVS merely prolongs an 'existence' rather than a 'life'.[60] It is

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[53] See section 2.3.

[54] See section 2.2.2.

[55] McGee (ch2 n255).

[56] ibid.

[57] D Orentlicher, *Matters of Life and Death: Making Moral Theory Work in Medical Ethics and the Law* (Princeton University Press 2001) 29.

[58] Bland's case (ch1 n12).

[59] J Harris, *The Value of Life, An Introduction to Medical Ethics* (Routledge & Kegan Paul plc 1985) 26.

[60] McLean (ch2 n223).

possible to justify the withdrawal of treatment in Bland's case by applying Harris' argument that the intrinsic value of 'human life' does not include 'mere existence' with no possibility of future consciousness. However, if the doctrine of sanctity of life is absolute then we should not allow the withholding or withdrawal of life-sustaining treatment. All lives will have to be preserved without exception, even Bland's.

3.3.2 *Right to self-determination*

The right to self-determination is an ethical principle which underpins the concept of personal autonomy. It is argued here that ending one's own life is the ultimate act of self-determination. As Brock argues:

> self-determination is valuable because it permits people to form and to live in accordance with their own conception of a good life, at least within the bounds of justice and consistent with not preventing others from doing so as well. In exercising self-determination people exercise significant control over their lives and thereby take responsibility for their lives and for the kinds of persons they become … if self-determination is a fundamental value, then the great variability among people on this question makes it especially important that individuals control to the extent possible the manner, circumstances, and timing of their dying and death.[61]

As discussed in Chapter Two, self-determination in terms of controlling the manner, circumstances, and timing of one's own death is already evident in English law. Not only is suicide no longer a crime, a patient is also permitted to refuse life-sustaining treatment,[62] even to the extent of making an advance refusal of such treatment. With particular reference to a competent patient's refusal of life-sustaining treatment, Lord Donaldson in *Re T* said:

> This situation gives rise to a conflict between two interests, that of the patient and that of the society in which he lives. The patient's interest consists of his right to self-determination — his right to live his own life how he wishes, even if it will damage his health or lead to his premature death. Society's interest is in upholding the concept that all human life is

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[61] DW Brock, *Life and Death: Philosophical Essays in Biomedical Ethics* (CUP 1993),205-206.

[62] See *Re B (Adult: Refusal of Treatment)* (ch1 n42).

> sacred and should be preserved if at all possible. It is well established that in the ultimate the right of the individual is paramount.[63]

Dworkin argues that the right to assisted death should be a part of an individual's moral right to self-determination.[64] It is however argued that assisted death is not a private matter of self-determination, but rather an act that requires the assistance of others, and the approval of society.[65]

3.3.3 *Professional ethics*

The GMC, the independent regulator for British physicians,[66] opposes assisted death. The role of physicians, according to the GMC, is to treat illness or, where that is not possible, to relieve its symptoms[67] and thereby improve quality of life.[68] In its evidence to the House of Lords' Select Committee on the ADTI Bill 2004, the GMC stated:

> A change in the law to allow physician-assisted [death] would have profound implications for the role and responsibilities of [physicians] and their relationships with patients. Acting with the primary intention to hasten a patient's death would be difficult to reconcile with the medical ethical principles of beneficence and non-maleficence.[69]

The view of the British Medical Association ('BMA'), which represents physicians throughout the UK, is similar to the GMC. Since 2006, the general consensus of the BMA has remained that UK law should not be changed to permit physician-assisted death.[70] The BMA is concerned that giving a terminally ill patient a legal right to end their life with physician assistance, even where that assistance is limited to assessment,

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[63] *Re T (Adult: Refusal of Treatment)* (ch2 n248) 661.

[64] R Dworkin et al, 'Assisted Suicide: The Philosophers' Brief' *New York Review of Books* (New York,27 March 1997) 41-47.

[65] D Callahan, 'When Self-Determination Runs Amok' (1992)22(2) Hastings Cent.Rep 50,52.

[66] The GMC may ban a physician from practising medicine and remove them from the medical register if they fall short of the medical standards required by the GMC.

[67] See section 3.4.3.

[68] GMC, 'The role of the GMC' <www.gmc-uk.org/about/role.asp> accessed 7 March 2013.

[69] 2004 HL Select Committee Report, Vol I (ch1 n49) 112. See section 2.4.2 on 'Assisted Dying for the Terminally Ill Bill 2004'.

[70] E Pickover, 'BMA rejects assisted suicide move as one delegate likens it to murder' *The Independent* (London, 27 June 2012).See also: BMA, 'What is current BMA policy on assisted dying?' <http://bma.org.uk/practical-support-at-work/ethics/bma-policy-assisted-dying> accessed 7 March 2013.

verification or prescribing medication, could alter the ethics of medical practice, which is to improve a patient's quality of life, rather than to bring it to an end.

Like the GMC, the Royal College of Surgeons ('RCS') also stresses the role of surgeons to alleviate and control symptoms. The RCS is of the belief that adequate palliative care is able to address the needs of the terminally ill. In its written evidence to the 2010 Commission on Assisted Dying (discussed in Chapter Two), the RCS stated that while some patients have distressing symptoms, 'a compassionate response to these situations should involve empathy and working hard to control symptoms and not simply to hasten death'.[71]

The underlying ethics of medicine in England and Wales is strongly influenced by the ancient Hippocratic Oath, which emphasises three objectives for the physician — to cure or heal a patient of their illness or disease, to ease the intensity of a patient's pain and suffering, and to cease futile burdensome treatment.[72] Thus, the Hippocratic Oath takes into account palliative care, the doctrine of double effect, and the withdrawal and withholding of life-sustaining treatment.

It is argued that there is a contradiction in the underlying ethics of medicine. This is evidenced by the fact that physicians can indirectly hasten death through the withdrawal or withholding of life-sustaining treatment, yet the direct and deliberate assistance to die, at a patient's request, is opposed. The views of the BMA are clearly expressed in its August 2009 note, where it states that life-sustaining treatment can be withheld or withdrawn when it is unable to benefit an incompetent patient and is not in their best interests.[73] Similarly, the more recent 2010 guidelines of the GMC on treatment and care towards the end of life state that, where death is imminent and ANH is already in use, it may be appropriate to withdraw such treatment if it is considered that the burdens outweigh the possible benefits to the patient.[74] In this regard, the GMC and BMA's opposition to a law on physician-assisted death based on the grounds that it is against the underlying ethics of medicine is morally indefensible.

Contrary to the tenor of present ethical and legal thinking, there should be engagement by the medical profession with patients seeking an assisted suicide. Physicians would be

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[71] *Report of the Commission on Assisted Dying* (ch1 n51) 79.

[72] H ten Have and J Welie, *Death and Medical Power, An Ethical Analysis of Dutch Euthanasia Practice* (Open University Press 2005) 23.

[73] BMA, *End-of-Life Decisions: Views of the BMA* (August 2009).

[74] GMC, *Treatment and care towards the end of life* (ch2 n278) para 123.

able to investigate the reasons why patients want to die and explore whether there are any treatment alternatives.[75] Physicians should be involved in some of the procedural safeguards necessary for a law on assisted death, such as ensuring that a patient is well informed about their condition, prognosis, and possible treatments and ensuring that all reasonable means have been taken to improve the quality of the patient's life.[76]

The January 2013 GMC guidance on 'when a patient seeks advice or information about assistance to die' addresses the concerns of physicians over criminal liability arising from end-of-life conversations, and whether physicians might be implicated merely by answering questions or providing information. The guidance advises physicians to merely 'listen and discuss' a patient's reasons and 'provide [them] with the information they want or need so they can make decisions about their health or health care.'[77] It also considers that the mere provision of advice or information on the assisted suicide law, and access to medical records for purposes of an assisted death abroad are unlikely to result in an investigation.[78]

It is argued that as the professional conduct of physicians in England and Wales is already controlled by the GMC's professional codes of practice, and subject to its disciplinary processes, a mechanism already exists to oversee and regulate the medical practices of physicians.[79] As noted in Chapter Two, there is evidence that physician-assisted death is to some extent already being performed in an unregulated fashion.[80] However, it is submitted here that the legalisation of physician-assisted suicide, with appropriate regulatory procedures, and taking into account adequate palliative care, may in fact reduce the likelihood of covert and unlawful practices in England and Wales.[81] Overall, as the conduct of physicians is already controlled by the GMC, it would be no more likely for a physician to abuse a law on assisted death if legally permitted to assist

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[75] Mullock (ch2 n103) 469.

[76] DW Brock, 'Voluntary Active Euthanasia' (1992)22 Hastings Cent.Rep 10.

[77] GMC, *Explanatory guidance: When a patient seeks advice or information about assistance to die* (January 2013). See also: John Bingham, 'Assisted suicide: GMC signals doctors safe to provide medical records to Dignitas patients' *The Telegraph* (London,1 February 2013).

[78] GMC, *Guidance for the Investigation Committee and case examiners when considering allegations about a doctor's involvement in encouraging or assisting suicide* (January 2013).

[79] RA Knox, 'Poll: Americans Favor Mercy Killing' *Boston Globe* (Boston,3 November 1991).

[80] See sections 2.2.3 and 2.3.1.

[81] TE Quill et al, 'Care of the Hopelessly Ill: Proposed Clinical Criteria for Physician-Assisted Suicide' (1992)327 N Engl J Med 1380,1383.

in a patient’s death.[82] Similarly, no evidence of such an increased likelihood of abuse is found in Chapter Six, from a review of the Netherlands, Belgium, and Oregon.

Presently, the medical profession in England and Wales is not unanimously opposed to the legalisation of physician-assisted death. The Healthcare Professionals for Assisted Dying (‘HPAD’) is a group of healthcare professionals who do not believe that the terminally ill should have to suffer or travel abroad to a right-to-die organisation for an assisted suicide.[83] Besides access to good quality end-of-life care, it supports a change in the law to allow mentally competent terminally ill adults the choice of an assisted death, within upfront safeguards. It argues that for those with terminal conditions, the dying process becomes a failure if the patient suffers an undignified death.[84]

As noted in Chapter Two, the results of recent surveys in the UK show that the majority of physicians oppose the legalisation of assisted death by physicians. Seale’s 2007-2008 survey on doctors’ attitudes to physician-assisted death in the UK found that 35.2% of doctors surveyed supported physician-assisted suicide for the terminally ill, whilst 34% of doctors thought that doctors should be able to perform voluntary euthanasia[85] on the terminally ill.[86] The survey also found that those in favour of physician-assisted death frequently qualify their support, by stressing a need for safeguards and adequate palliative care. Seale’s survey also noted that those opposing assisted death are more likely to be palliative care specialists. Physicians who were in favour of a law on assisted death expressed concern about involvement by the medical profession, and supported a law that might not involve physicians.[87] The concern was the impact of physician-assisted death on the physician-patient relationship and the relationship between the medical profession and society in general.[88] A more recent UK study by McCormack et al in 2011, on the attitudes of UK doctors, found even higher opposition amongst doctors to assisted suicide and voluntary euthanasia. Only 24.9% of doctors were willing to perform physician-assisted suicide, and 22.7% of doctors were willing to perform voluntary euthanasia.[89] Lee at al’s 2007 survey on doctors’ opinions on the

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[82] ibid.

[83] *HPAD* <www.hpad.org.uk> accessed 8 March 2013.

[84] ibid.

[85] ‘Voluntary euthanasia’ (ch1 n7).

[86] Seale (ch2 n173).

[87] ibid 208-209.

[88] Hoffenberg (ch1 n85). See section 3.4.1 on ‘public trust in physicians’.

[89] McCormack (ch2 n380).

legalisation of physician-assisted suicide also showed that physicians working closest with the terminally ill are those with the strongest objections to legalising physician-assisted death.[90] These are legitimate concerns and are considered further in section 3.4.1, as well as Chapter Seven on the proposed law reform for England and Wales.

3.3.4 *The 'four-principle' model of medical ethics*

There are four widely accepted general principles of medical ethics that provide a framework for analysing ethical issues — respect for autonomy, non-maleficence, beneficence and justice in medical care. This 'four-principle model' was developed by Beauchamp and Childress in 1979 as an approach to ethical dilemmas in medicine.[91] Each principle is discussed in further detail below.

– *Respect for autonomy*

The first principle of medical ethics under the four-principle model, respect for patient autonomy, is correctly heralded by Pellegrino as the dominant principle shaping medical ethics, the law and the physician-patient relationship.[92] As discussed in section 3.3.2, patient autonomy is based on the underlying ethical influence of the right to self-determination. Patient autonomy encompasses a belief that each patient has the right to make unconstrained treatment decisions about matters that primarily affect themselves.[93] As discussed in Chapter Two, competent patients have the absolute right to make autonomous treatment decisions, notwithstanding that the reasons for making such decisions may be irrational.[94]

To enable patients to make autonomous treatment decisions that are fully informed and considered, they require adequate medical information from their physicians.[95] For this purpose, the GMC's *Consent guidance: patients and doctors making decisions together* provides that physicians should discuss with their patients their condition and treatment options. Bearing in mind the wishes of their patients, physicians should share

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[90] Lee (ch2 n174).

[91] Beauchamp and Childress (n2).

[92] ED Pellegrino, 'Patient and Physician Autonomy: Conflicting Rights and Obligations in the Physician-Patient Relationship' (1994)10 J Contemporary Health Law& Policy 47,47.

[93] TA Mappes and JS Zembaty, *Biomedical Ethics* (3rd edn, McGraw-Hill 1991) 25.

[94] *Re T (Adult: Refusal of Treatment)* (ch2 n248) 653.

[95] M Karlsson et al, 'Dying cancer patients' own opinions on euthanasia: An expression of autonomy? A qualitative study' (2012)26(1) Palliative Medicine 34.

information in proportion to the nature of their patients' condition, treatment, and seriousness of any side effects, complications or other risks.[96] As discussed in Chapter Two, English law presently defers to patient autonomy in cases of suicide, and competent[97] or advance[98] refusals of life-sustaining treatment. It is submitted here that there is an inconsistency in English law which acknowledges the right to autonomy when allowing a person to refuse life-sustaining treatment, but denies a similar right to a patient who requests death from their physician.[99]

Salem cogently argues that autonomy is the right to act and govern oneself in accordance with one's own private beliefs, values, and choices without interference as long as one's behaviour does not harm others.[100] Salem's definition of autonomy can be best explained by Mill's principle of liberty:

> [T]he only purpose for which power can be rightfully exercised over any member of a civilized community, against his will, is to prevent harm to others. His own good, either physical or moral, is not a sufficient warrant. He cannot rightfully be compelled to do or forbear because it will be better for him to do so, because it will make him happier, because, in the opinions of others, to do so would be wise, or even right. ... Over himself, over his own body and mind, the individual is sovereign.[101]

It is accepted that a terminally ill patient's decision to end their own life should not be interfered with on the grounds that others are acting for the patient's own good in preventing the death.[102]

Beauchamp argues that the right to request an assisted death is an extension of a patient's autonomous right to refuse life-sustaining treatment.[103] It is however contended that a patient can only be administered treatment with their consent. A physician's obligation to subsequently comply with the patient's refusal of life-sustaining treatment

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[96] See GMC, *Consent guidance: patients and doctors making decisions together: About the guidance* <www.gmc-uk.org/guidance/ethical_guidance/consent_guidance_index.asp> accessed 22 August 2013. See also: GMC, *Consent: patients and doctors making decisions together* (2008).

[97] See *Re B (Adult: Refusal of Treatment)* (ch1 n42).

[98] See section 2.3.3.

[99] TL Beauchamp & JF Childress, *Principles of Biomedical Ethics* (4th edn, OUP 1994) 286.

[100] T Salem, 'Physician Assisted Suicide Promoting Autonomy or Medicalizing Suicide?' (1999)29(3) Hastings Cent.Rep 30.

[101] JS Mill, *On Liberty* (Alburey Castell ed, Appleton-Century-Crofts 1947) 9-10.

[102] J Rachels, *The End of Life: Euthanasia and Morality* (P Singer ed, OUP 1986) 181.

[103] TL Beauchamp, 'The Justification of Physician-Assisted Deaths' (1996)29(4) Ind.L.Rev. 1173,1192-1193.

cannot be the basis for imputing an obligation on the physician to assist with the patient's request for assisted death.[104] McLean makes a compelling argument that in cases of assisted death there is a combination of individual autonomy, in which private morality is taken into account, and relational autonomy, in which public morality and the interests of others are given weight. It is this combination which allows for the refusal of life-sustaining treatment, but denies a right to assisted death.[105]

It is argued that the wish for assisted death may be less an act of surrender due to unbearable suffering, and more the expression of autonomy and control over the timing and manner of one's death.[106] As Seale and Addington-Hall assert, 'Requests for help to die may indicate not that patients are giving up in the face of suffering, but that they are positively asserting their desire to control events.'[107] This is supported by studies of physician-assisted suicides under the DDA in Oregon (discussed in Chapter Five). These found that the majority of terminally ill patients never use the lethal medication prescribed pursuant to that Act. It is accepted that those patients who don't immediately self-administer their prescribed lethal medication may be comforted just by the knowledge that they are in control of the timing and manner of their death, and that they have not been abandoned by their physicians. As the final physical act of administering the means of suicide in any physician-assisted suicide is the patient's, a patient maintains control over their death when given the right to self-administer the lethal drugs.[108]

It is also argued that in the case of physician-assisted suicide, a physician must also be willing to assist the patient and must not be compelled to do so. In such cases, the physician must be allowed an equal opportunity to exercise their own autonomy,[109] as physician-assisted suicide involves the interpersonal dynamics of the physician-patient relationship, where there is a mutual decision between the physician and patient.[110] Rachels argues that Mill's principle of liberty[111] applies equally to cases of physician-

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[104] JL Bernat et al, 'Patient refusal of hydration and nutrition. An alternative to physician-assisted suicide or voluntary active euthanasia' (1993)153 Arch Intern Med 2723.

[105] SAM McLean, *Autonomy, Consent and the Law* (Routledge-Cavendish 2010) 127.

[106] C Seale et al, 'Awareness of dying: prevalence, causes and consequences' (1997)45(3) Soc Sci Med 477.

[107] Seale and Addington-Hall (n32).

[108] SJ Ziegler and G Bosshard, 'Role of non-governmental organisations in physician assisted suicide' (2007)334 BMJ 295.

[109] I Beech, 'Suicide and voluntary active euthanasia: why the difference in attitude?' (1995)2 Nursing Ethics 161.

[110] Salem (n100).

[111] See text to n101 for Mill's principle of liberty.

assisted suicide, as the patient and physician act together in a private matter, where no one else's interests are involved. According to Rachels, if we are to respect the right to liberty of dying patients, we must respect the right to physician-assisted suicides performed by willing physicians.[112] However, it is submitted that respect for a patient's autonomy should not disregard the importance of society's interests. As was observed by the 1994 House of Lords' Select Committee on Medical Ethics, 'the issue of [assisted death] is one in which the interest of the individual cannot be separated from the interest of society as a whole.'[113] Blondeau, too, correctly observes that just as life is a social practice, dying is also a social practice. It does not happen outside of a social network.[114]

– *Non-maleficence and beneficence*

The second and third principles of medical ethics under the four-principle model are non-maleficence and beneficence. As noted by Beauchamp and Childress, 'non-maleficence' means that one has an obligation not to intentionally harm others, whilst 'beneficence' means that one has a duty to act for the benefit of others. Physicians must consider these two principles together and aim at producing a net benefit for their patients.[115] These two principles are strongly influenced by the ancient Hippocratic Oath which aimed to provide net medical benefit to patients with minimal harm.[116] These principles are demonstrated in cases where futile life-sustaining treatment is withdrawn or withheld from incompetent patients, as with Bland's case.[117] As Rachels forcefully argues, if the only effect of maintaining life-sustaining treatment is to prolong a patient's suffering, this would offend the principle of non-maleficence. As such, the withdrawal of treatment would be the better treatment decision with the least harmful effects.[118]

As correctly observed by Huxtable, there is no straightforward application of these medical ethical principles. Some may oppose the legalisation of physician-assisted death

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[112] Rachels (n102) 182.

[113] *Report of the Select Committee on Medical Ethics* (1993-94, HL21-1) (HMSO 1994) 48.

[114] D Blondeau (ed), *Ethique et soins infirmiers* [Ethics and nursing care] (Les Presses de l'Université de Montréal 1999) 229–42.

[115] Beauchamp & Childress (ch2 n253)113.

[116] R Gillon, 'Medical ethics: four principles plus attention to scope' (1994)309 BMJ 184.

[117] Bland's case (ch1 n12), see section 2.3.3.

[118] J Rachels, 'Active and Passive Euthanasia' (1975)292 N Engl J Med 78.

by regarding life as a benefit based on an absolute view of the doctrine of sanctity of life, whilst others may favour the legalisation of physician-assisted death by prioritising one's quality of life over sanctity of life.[119] Nevertheless, it is argued that it is important to be aware of a patient's own assessment of what is harmful or of benefit to them.[120] It is essential for physicians to take account of a patient's preferences about their own medical treatment.[121] Although 'beneficence' requires a positive benefit to be conferred on the patient, it is accepted that even by assisting a suicide, a physician is conferring a positive benefit by providing the ultimate relief for a patient's pain and suffering.[122]

– *Justice in medical care*

The fourth principle of medical ethics under the four-principle model is justice in medical care. Under this principle, all patients have an equal right to be treated, and medical care is to be distributed fairly to all patients. Patients should receive treatment according to their needs, physicians should provide treatment according to what is possible, and there should be a just distribution of care across all patients.[123] Besides taking account of what is in the best interests of the patient, a physician must also consider the needs of other patients and prioritise and distribute health resources across all patients accordingly.[124] As observed by Vincent, the cessation of futile life-sustaining treatment promotes the principle of justice in medical care, as the continuation of such treatment demands costs, time and energy that could be better used on other patients.[125] On the basis of this principle, physician-assisted suicide should be permitted to terminally ill patients who make a competent request for it, as this would free up medical care and resources that could provide a greater benefit to others.

3.3.5 *Consequentialism and deontology*

Consequentialism and deontology are two ethical measures for assessing the morality of actions. According to consequentialists, the consequences of one's actions govern the

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[119] R Huxtable, 'Re B (Consent to Treatment: Capacity): A right to die or is it right to die?' (2002)14(3) CFLQ 341,343.

[120] P McCormack, 'Quality of life and the right to die: an ethical dilemma' (1998)28(1) J Advanced Nursing 63.

[121] Gillon (n116).

[122] Harris (ch1 n81).

[123] Gillon (n116).

[124] Karlsson (n95).

[125] JL Vincent, 'Ethical principles in end-of-life decisions in different European countries' (2004)134 Swiss Medical Weekly 65.

morality of those actions.[126] The course that results in the best overall outcome with the most benefit is the morally right course of action.[127] However, in applying this ethical measure, one challenge is that one does not always know the consequences of one's actions. On the other hand, deontology holds that certain actions are intrinsically right or wrong regardless of their consequences.[128] The deontological measure starts from a premise that human beings have absolute duties and obligations.[129]

It is contended that medical ethical reasoning in England and Wales is primarily deontological in nature, as it relies on moral absolutes. The application of a deontological ethical measure is demonstrated by Bland's case.[130] The House of Lords in Bland made a distinction between 'killing' and 'omitting to treat and letting someone die' to morally justify the withdrawal of life-sustaining treatment from an incompetent patient who was in a PVS.[131] In Bland's case, the patient was considered to have died from his underlying injury. However, as 'killing' and 'letting someone die' both have the same consequences, such a distinction does not work under a consequentialist ethical measure.[132] As Lord Mustill observed in Bland's case, 'however much the terminologies ['act' and 'omission'] may differ the ethical status of the two courses of action [pursuant to consequentialism] is for all relevant purposes indistinguishable'.[133] Thus, as argued by Gillon, if 'letting someone die' is morally acceptable, then an 'act of killing' with the same consequences would also be acceptable under consequentialism.[134]

It follows from this that the present prohibition on assisted death may be morally justified under consequentialism. The legalisation of assisted death may have a negative impact on the value of life in society at large. It may also have a negative effect on the relationship between patients and physicians.[135] The vulnerable may feel pressured to

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[126] R Huxtable, 'Denying Life: The Sanctity of Life Doctrine in English Law' (2002)25(3) Retfærd 60, 64.

[127] R Gillon, *Philosophical Medical Ethics* (4th edn, John Wiley & Sons Ltd 1992).

[128] L Goodhall, 'Tube feeding dilemmas: can artificial nutrition and hydration be legally or ethically withheld or withdrawn?' (1997)25 J Advanced Nursing 217.

[129] K Wright, *Medical Treatment (Prevention of Euthanasia) Bill, Bill 12 of 1999-2000,* House of Commons Library Research Paper 00/8 (24 January 2000).

[130] Bland's case (ch1 n12).

[131] Beauchamp and Childress (ch2 n253) 140.

[132] Wright (n129).

[133] Bland's case (ch1 n12) 885.

[134] Gillon (n127) 129.

[135] See section 3.4.1.

request an assisted death,[136] and there may no longer be any motivation for physicians to look for ways to address a patient's pain and suffering[137] or to research a cure for terminal illness.

However, the legalisation of assisted death could be justified by applying a deontological and a consequentialist ethical measure. The deontological approach is that respect for the personal autonomy of a terminally ill person who is suffering unbearably should be fundamental, and should override sanctity of life.[138] Meanwhile a consequentialist approach is that a law on assisted death with adequate safeguards would provide the best overall outcome for society.

3.3.6 *Doctrine of double effect*

Under the doctrine of double effect, a physician is permitted to administer large doses of palliative drugs to a terminally ill patient, even though the toxicity of those drugs will inevitably shorten the patient's life. As discussed in Chapter Two, the English courts have held that such treatment is lawful, even if the incidental effect of the lethal drugs is to hasten a patient's death.[139] Such treatment is justified because the primary intention is to relieve pain, with the hastening of death regarded as a foreseen but unintended consequence.[140] It is, however, argued that if it is probable that a known side effect will occur, then a physician should accept the moral responsibility for such effects that they foresee as inevitable, even though they do not intend them.[141] As argued by Harris, a person must be morally responsible for all of the consequences of their actions, whether direct or indirect.[142] Cotton persuasively asserts, '[d]ying patients are given larger and larger doses of morphine. We talk about the "double effect", and know jolly well we are sedating them into oblivion, providing pain relief but also providing permanent relief, and we don't tell them'.[143]

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[136] See section 3.4.6.

[137] See section 3.4.3.

[138] McCormack (n120).

[139] Palmer (ch2 n222) 375.

[140] PC Snelling, 'Consequences Count: Against Absolutism at the End of Life' (2004) J Advanced Nursing 350.

[141] Gillon (n127) 135.

[142] J Harris, 'The Philosophical Case Against the Philosophical Case Against Euthanasia' in *Euthanasia Examined: Ethical, Clinical and Legal Perspectives* (Keown J ed, CUP 1997), 36-40.

[143] P Cotton, 'Medicine's Position is Both Pivotal and Precarious in Assisted-Suicide Debate' (1995)273 JAMA 363,363.

As was argued in Chapter Two, the doctrine of double effect calls into question the moral defensibility of the current prohibition on assisted death. Physicians are not permitted to intentionally assist a patient to die, but may (under the doctrine) knowingly hasten a patient's death provided that it is an unintended side effect of treatment. As observed by Kass and Lund, the distinction between physician-assisted death and the potential double effect of palliative medication is a 'blur'.[144] It is difficult to maintain a moral and legal difference between, on the one hand, a high dosage of palliative medication which is known to cause death over a few days, and on the other hand, purposefully assisting patients to die quickly from a lethal medication.[145]

3.3.7 *Quality of life*

An important driving force behind terminally ill patients seeking an assisted death is their poor quality of life. The terminally ill often fear the disintegration of their bodies and minds.[146] Studies have found that one of the worst aspects of the quality of life of terminally ill patients is the loss of functioning, control and independence,[147] which may lead to feelings of being a burden to others. This is demonstrated in Price et al's 2010 study, which investigated the desire for a hastened death in patients receiving palliative care. The study found that participants who had a higher quality of life and physical, cognitive and social functioning were less likely to have a desire for a hastened death.[148]

It is argued that a terminally ill patient who is competent should be able to decide at what point their quality of life is so poor and unacceptable for them to continue living.[149] As discussed in Chapter Two, in the case of *Re B*, the patient found her quality of life to be so poor that continued life for her would have been worse than no further life at all.[150] Finding her quality of life to be of an unacceptable standard, the patient refused life-sustaining treatment. It is submitted that English courts already accept quality of life judgements in end-of-life decisions involving incompetent patients (discussed in

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[144] LR Kass & N Lund, 'Physician-Assisted Suicide, Medical Ethics and the Future of the Medical Profession' (1996)35 Duq.L.Rev. 395, 422-423.

[145] RRA Syme, 'A Patient's Right to a Good Death' (1991)154 Med J Aust 203, 204.

[146] C Bollman, 'A Dignified Death? Don't Forget About The Physically Disabled And Those Not Terminally Ill: An Analysis Of Physician Assisted Suicide Laws' (2010)34 S.Ill.U.L.J. 395,411.

[147] CM Parkes, 'Terminal care: evaluation of inpatient service at St Christopher's Hospice. Part I. Views of surviving spouses on effects of the service on the patient' (1979)55 Postgraduate Medical Journal 517.

[148] Price (ch1 n45).

[149] Clery (ch1 n61) 37.

[150] *Re B (Adult: Refusal of Treatment)* (ch1 n42).

Chapter Four). A quality of life judgement was evident in Bland's case, where the House of Lords allowed the withdrawal of life-sustaining treatment from an incompetent patient who was in a PVS.[151] The House of Lords found Bland's quality of life to be so poor that the provision of ANH would have been futile, burdensome and of no benefit to him. Due to the importance of the issue, quality of life is addressed in greater detail in Chapter Four.

3.3.8 *Paternalism*

The current law in England and Wales supports a paternalistic approach by the medical profession towards end-of-life medical decisions. This is demonstrated by the English courts in allowing physicians to withdraw or withhold life-sustaining treatment from incompetent patients.[152] Medical ethicists argue that because beneficence is a guiding principle of medical ethics,[153] it allows physicians to make medical decisions in the best interests of their incompetent patients.[154] It is accepted that medical paternalism should be the approach to medical decision-making in cases involving incompetent patients.[155] As commentators have observed, decisions involving the termination of futile life-sustaining treatment require an expert medical judgement by physicians who have the required knowledge, expertise and experience.[156]

Nevertheless, beneficence may also be a guise for medical paternalism towards competent patients.[157] For example, end-of-life medical decisions involving a 'double effect' may leave a patient at the mercy of their physician's motivations and intentions.[158] The law under the doctrine of double effect is in effect stipulating that the intention of a physician is more important than a patient's right to self-determination.[159]

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[151] Bland's case (ch1 n12).

[152] ibid. See also *Burke* (ch2 n277).

[153] TL Beauchamp & JF Childress, *Principles of Biomedical Ethics* (3rd edn, OUP 1989) 209.

[154] Pellegrino (n92) 50-51.

[155] MS Komrad, 'A defence of medical paternalism: maximising patients' autonomy' (1983)9 J Medical Ethics 38.

[156] AL Caplan et al, 'The Role of Guidelines in the Practice of Physician-Assisted Suicide' (2000)132 Ann Intern Med 476,478-79. See also: DW Brock, 'Medical decisions at the end of life' in H Kuhse and P Singer (eds), *A Companion to Bioethics* (Blackwell Publishing 2001) 231.

[157] AE Clark, 'Autonomy and Death' (1997)71 Tul.L.Rev. 45,116.

[158] RS Magnusson, 'The Devil's Choice: Re-Thinking Law, Ethics, and Symptom Relief in Palliative Care' (2000) J.L.Med& Ethics 559,567.

[159] Rothschild (ch2 n228) 74.

The case of *Re B* (discussed in Chapter Two) also demonstrates that, 'If beneficence is left entirely to the subjective judgment of [physicians] it … easily becomes an excuse for paternalism'.[160] In *Re B*,[161] a competent patient exercised patient autonomy and requested that her life-sustaining ventilator be switched off. The patient's physicians claimed that she lacked competence, and refused her request saying that the refusal was in her best interests. Dame Butler-Sloss held:

> the principles of autonomy and beneficence would appear to be in conflict in this case. In accordance with the principle [of autonomy], the right of the competent patient to request cessation of treatment must prevail over the natural desire of the medical and nursing profession to try to keep her alive.[162]

Her judgment further stated, 'There is a serious danger, exemplified in this case, of a benevolent paternalism which does not embrace recognition of the personal autonomy of the severely disabled patient.'[163]

It is however submitted that where patients experience diminished autonomy, medical paternalism is justified.[164] As Marzuk argues, there are some human conditions in which people are not capable of enjoying a full measure of autonomy. Patients may differ in intellectual ability, may have different medical experiences, may have an illness that affects higher cognitive functions, or may have a strong emotional reaction to illness that precludes their objective processing of medical information.[165] Komrad soundly asserts that the physician-patient relationship is a dynamic process, where one's degree of autonomy is not fixed but may fluctuate during the course of an illness.[166] As a patient's capacity for autonomy increases, a physician's paternalism which nurtures that autonomy decreases.[167]

The current prohibition on assisted suicide in England and Wales itself displays state paternalism. State paternalism was demonstrated in *Pretty*, when the ECtHR held that

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[160] C Faulder, *Whose Body is it? The Troubling Issue of Informed Consent* (Virago 1985) 158.

[161] *Re B (Adult: Refusal of Treatment)* (ch1 n42).

[162] ibid [27].

[163] ibid 472 (Dame Butler-Sloss).

[164] Komrad (n155).

[165] P Marzuk, 'The right kind of paternalism' (1985)313 N Engl J Med 1474.

[166] Komrad (n155).

[167] ibid.

the infringement of Pretty's right to private life under Article 8(1) of the ECHR was justified under Article 8(2),[168] and that any arguments premised on respect for a patient's autonomy were outweighed by the state's interest in 'preserving life and protecting the vulnerable'.[169] State paternalism was also evident in *Purdy*, in which Baroness Hale held that the DPP's prosecuting policy should not only be based on one's right to autonomy, but also on protecting people who are vulnerable to various sorts of pressures.[170]

It is submitted that any legalisation of assisted death should not be absolutely based on personal autonomy, but should also be mindful of appropriate levels of medical and state paternalism, to avoid abuse of the law, and to protect the vulnerable in society.

3.3.9 *Increasing scarcity of healthcare resources*

An important factor in the debate concerning assisted death is the effort being made to save limited healthcare resources for other, purportedly more beneficial, uses especially in a publicly funded health care system.[171] As efforts are made to contain health care expenditure and ensure the just allocation of limited resources, there has been a growing recognition by healthcare authorities of the benefit of respecting a patient's choice not to be subjected to prolonged and unwanted medical treatment.[172] A consequentialist ethical measure is of particular significance in a situation where there are limited healthcare resources.[173] A consequentialist would question the morality of artificially maintaining a patient in a PVS, given its drain on limited medical resources.[174] For a consequentialist, such resources should preferably be apportioned in ways that create greater benefit.[175]

It is contended here that the legalisation of assisted death would be effective in freeing up limited healthcare resources for other patients and thus promoting the interests of society as a whole.[176] Nevertheless, Somerville persuasively asserts that:

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[168] art 8(2) (ch2 n25).

[169] *Pretty* (ECtHR)(ch2 n22)[36]-[37],[48].

[170] *Purdy* (HL)(ch1 n31)[65].

[171] Somerville (n29) 5.

[172] Otlowski (ch1 n88) 162.

[173] Goodhall (n128).

[174] ibid.

[175] ibid.

[176] MA Somerville, *Death Talk: The Case Against Euthanasia and Physician-Assisted Suicide* (McGill-Queen's University Press 2001) 42.

> the greatest danger of … [legalising assisted death] would come from an overemphasis of [societal interests], [for example, freeing up limited healthcare resources] at the expense of individual rights. Such an outcome would be ironic if the introduction of [assisted death] were seen as necessary, as often claimed by advocates, to respect and promote individual rights.[177]

Somerville’s argument involves concerns of a slippery slope, in which a scarcity of healthcare resources may cause undue pressure on patients to opt for an assisted death.

3.4 Other factors

Having considered the social and ethical influences which affect the law on end-of-life medical decisions and the debate on assisted death in sections 3.2 and 3.3, this section will now consider other significant factors having an impact on them.

3.4.1 *Public trust in physicians*

The issue of public trust in physicians is highly relevant to the acceptability of a proposal for law reform on assisted death in England and Wales. The physician-patient relationship has often been described as a ‘healing relationship’ in which the physician restores the patient to health, or assists the patient in coping with illness, disease, or disability, and even death where a cure is not possible.[178] An objection against the legalisation of physician-assisted death is that this would undermine the public’s trust in the medical profession, and a patient’s faith in their physician. A patient may feel that their physician has given up on them and no longer feels the need to explore other treatment options.[179] Whilst Harris et al acknowledge these concerns, they still assert that physician-assisted death is ethically appropriate.[180] They argue that when respecting a patient’s personal autonomy and assisting in their suicide, a physician would be exercising compassion by providing the ultimate relief for pain and suffering.

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[177] ibid.

[178] Pellegrino (ch2 n254) 98.

[179] R Cohen-Almagor, ‘Physician-Assisted Suicide - A Qualified Endorsement’ (2011)3(1) Amsterdam Law Forum 115.

[180] Harris (ch1 n81).

In this thesis the view is taken that the legalisation of physician-assisted suicide would not undermine the integrity of the medical profession. Physicians already regularly make end-of-life medical decisions in cases involving a ‘double effect’, and in cases where life-sustaining treatment is withdrawn or withheld from a patient, yet this has not undermined the public’s trust in physicians.[181] As argued by Wintersheimer, the medical profession was not impacted by the case of Bland, in which the withdrawal of ANH was allowed by the House of Lords.[182] This is despite the fact that the patient, Anthony Bland, effectively died slowly by starvation rather than by his underlying medical condition.[183] As convincingly observed by Chamberlain, rather than undermine the physician-patient relationship, by providing an assisted death the physician fulfils their patient’s wishes and maintains their trust.[184]

It is further argued that a physician’s involvement in a patient’s death should be judged in the context of all the medical interventions they made during the patient’s terminal illness.[185] For many patients, advances in medical technology may provide temporary remission from progression of their illness or disease.[186] However, such technology will eventually fail to assist and the patient’s condition will deteriorate, with the potential for prolonged suffering.[187] As appropriately argued by Benrubi, if physicians are responsible for the prolonged unbearable pain and suffering, due to advances in medical technology, they should then also be responsible for ending that pain and suffering. It would be unethical for the medical profession to bring patients to a state of extended suffering, and then abandon them there.[188] There may be a greater loss of trust in physicians if they hold terminally ill patients hostage to technology, rather than assisting them to die.[189]

Urofsky forcefully argues that physician-assisted death ‘demonstrate[s] a commitment to the patient’s well-being right up until the moment of death’.[190] Nevertheless, it is

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[181] TA Preston, ‘Professional Norms and Physician Attitudes toward Euthanasia’ (1994)22 J Law Med Ethics 36,39.

[182] Bland’s case (ch1 n12).

[183] DC Wintersheimer, ‘The Role of the Court in Terminating Nutrition and Hydration for Incompetent Patients’ (1995)10 Issues L.&Med. 453,460.

[184] KA Chamberlain, ‘Looking For a “Good Death”: The Elderly Terminally Ill’s Right to Die by Physician-Assisted Suicide’ (2009)17 Eld LJ 61,82–85.

[185] TA Preston, ‘Physician Involvement in Life-Ending Practices’ (1994-1995) 18 Seattle U.L.Rev 531,542.

[186] GI Benrubi, ‘Euthanasia – The Need for Procedural Safeguards’ (1992)326(3) N Engl J Med 197,198.

[187] ibid 198.

[188] ibid 198.

[189] Preston (n185) 542.

[190] MI Urofsky, ‘Do Go Gentle into That Good Night: Thoughts on Death, Suicide, Mortality and the Law’ (2007)59 Ark.L.Rev 819,832-833.

argued that any request for an assisted death should be treated as the trigger for a medical investigation into what other therapeutic options, such as hospice or palliative care, might effectively address the patient's condition.[191] For example, Ganzini et al's 2000 study on physicians' experiences with Oregon's DDA found that the control of pain or other symptoms, the referral to a hospice programme, or a trial of antidepressant medication had altered the requests of 46% of patients who had sought a lethal prescription.[192] The option for physician-assisted suicide should be one of last resort and not an alternative to other means of medicine. As noted by Baron, this would not only help ensure, but would reinforce, public trust in the integrity of the medical profession.[193]

As argued in Chapter Two, if physician-assisted suicide is legalised, patients would have the benefit of appropriate medical assistance from physicians who would have access to the necessary means for carrying out assisted death effectively.[194] This would reduce many of the risks associated with compassionate amateur assisted suicides.[195] Such risks include the means chosen for suicide being unreliable or inappropriately used.[196] Some physicians may even be able to screen for mental disorders, including depression, which may impair a patient's decision-making capacity.[197] Further, a physician present at a patient's suicide provides reassurance to the patient that the process will be carried out effectively,[198] and any complications that arise will be managed properly.[199]

As cogently argued by Clark, physician-assisted suicide should only be provided in the context of a meaningful physician-patient relationship.[200] This is to address the concern that a physician who has not developed a relationship with the patient may act too quickly and without adequate consideration of a patient's personal needs and medical history.[201] A meaningful relationship may also influence a patient's willingness to trust

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[191] CH Baron et al, 'A Model State Act to Authorize and Regulate Physician-Assisted Suicide' (1996)33 Harv.J.on Legis 1.

[192] Ganzini (ch1 n78) 563.

[193] Baron (n191).

[194] Brock (n76).

[195] See section 2.2.3.

[196] MP Battin, 'Euthanasia: The Way We Do It, The Way They Do It' (1991)6 J Pain Symptom Manage 298,301.

[197] Lewis (ch2 n97) 129-130.

[198] Baron (n191).

[199] Ziegler and Bosshard (n108) 296.

[200] Clark (n157) 128.

[201] TE Quill, *Death and Dignity; Making Choices and Taking Charge* (WW Norton, 1993) 162-63.

their physician. The need for an established relationship was also noted by the House of Lords' Select Committee on the ADTI Bill 2004 when it heard evidence of the long-standing physician-patient relationships which exist in Dutch practice.[202] These help physicians to assess whether their patient's request for assisted death is voluntary and well-considered, and whether their suffering is unbearable and without prospect of improvement.[203]

As Chamberlain soundly argues, a physician's duties to a terminally ill patient transcends simply keeping them alive in the face of excessive pain and suffering.[204] Similarly, it is submitted here that physician-assisted suicide should be a part of a continuum of medical treatment, palliative care, and compassion that will allow the terminally ill patient to feel that they are not abandoned by the medical profession at a time when they need it most.[205] As Quill and Battin persuasively claim:

> [If] assisted death … is to involve physicians, [it] cannot be solely a matter of patient choice; it must also be a response to medical distress, to actual or imminent suffering. The nature of the patient's suffering and why it is intolerable to the patient must be understood by the physician, who must then try to respond as a matter of mercy and in fulfilment of his commitment not to abandon the patient. Thus autonomy, mercy, and non-abandonment go hand in hand: for the physician to participate in assistance in dying, it must both be the patient's choice and help the patient avoid suffering that is intolerable or about to become so.[206]

As will be seen in the next section, advances in medical technology may lead physicians to focus on what is medically possible for prolonging life, rather than to focus on issues pertaining to a poor and unacceptable quality of life.

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[202] As will be discussed in section 5.2.2, the Dutch practice of euthanasia and assisted suicide involves *huisarten* [family-care physicians].

[203] 2004 HL Select Committee Report, Vol I (ch1 n49) 29.

[204] Chamberlain (n184) 82-85.

[205] Gostin (ch1 n68) 99.

[206] MP Battin and TE Quill, 'False Dichotomy versus Genuine Choice, The Argument over Physician-Assisted Dying' in TE Quill and MP Battin (eds), *Physician-Assisted Dying: The Case for Palliative Care and Patient Choice* (Johns Hopkins University Press 2004) 8.

3.4.2 *Advances in medical technology*

While most patients previously died of illnesses that medicine could not overcome, advances in medical technology and longevity have added new dimensions to the dying process. As Callahan aptly explains, ‘While technology has greatly improved our ability to prolong life in the face of severe illness, it has also increased our uncertainty over when such life extension is meaningful.’[207] He goes on to further state that, ‘often it is only one’s dying that is prolonged by technological brinkmanship’.[208] As noted in the judgment of Pretty’s case:

> in an era of growing medical sophistication combined with longer life expectancies, many people are concerned that they should not be forced to linger on in old age or in states of physical or mental decrepitude which conflict with strongly held ideas of self and personal identity.[209]

The view is accepted that advances in medical technology have further aggravated the issue of the ‘medicalisation of death’. Stringer defines the ‘medicalisation of death’ as a physician’s determined efforts to continue aggressive treatments for hopelessly ill patients. According to him, those who consider it impossible for medical technology to deliver a dignified death may view such aggressive treatments on the terminally ill to be inhumane, as they are responsible for ‘keeping us alive when we might be better off dead’.[210] As similarly observed by Seymour, advances in medical technology blur the boundaries between living and dying.[211] Otlowski too argues that medical technology often does nothing to improve a patient’s quality of life, but rather prolongs the dying process.[212]

It is submitted that a request for assisted death is often the result of a patient’s fear of an undignified prolongation of death. Advances in medical technology frequently lead to the isolation of the dying person and the dehumanisation of death.[213] As Somerville convincingly asserts, death has been institutionalised, de-personalised and de-humanised. It is often a medical event that takes place in a medical institution, where

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[207] D Callahan, *The Troubled Dream of Life: Living with Mortality* (Simon and Schuster 1993) 48-49.

[208] ibid 192-193.

[209] *Pretty* (ECtHR)(ch2 n22) [65].

[210] S Stringer, ‘Quality of death: humanisation versus medicalization’ (2007)6(3) Cancer Nursing Practice 23,26.

[211] JE Seymour, ‘Revisiting medicalization and “natural” death’ (1999)49 Soc Sci Med 691,692.

[212] Otlowski (ch1 n88).

[213] Seymour (n211) 692.

the person dying is alone and isolated.[214] Similarly, Illich observes that modern medicine has ‘brought the epoch of natural death to an end.’[215] Kastenbaum’s description of ‘phenomenological death’,[216] where dying people exist under sedation and trapped in an isolated state of suspended animation, may best depict the image of death most feared as a result of the advances in medical technology.[217] As Timmermans clearly argues, ‘the observation that … it is impossible for advanced medical technology and humane, dignified dying to co-exist becomes thus both an assumption and a normative conclusion’.[218]

As will be seen in the following section, palliative care and hospices assist to address this sense of isolation, depersonalisation, and loss of control that dying patients frequently suffer in hospitals, surrounded by medical technology.[219]

3.4.3 *Palliative care*

Those opposing a law on assisted death often argue that adequate palliative care can alleviate a patient’s desire for assisted death.[220] Studies in the UK show that suicidal patients who have expressed a strong desire for death have been known to subsequently change their views once given high-quality palliative care.[221] This is demonstrated by Price et al’s 2010 study which investigated the desire for a hastened death in patients receiving palliative care. The researchers noted that such a desire tends to fluctuate over time. The study found that a number of remedies available through palliative care services, such as symptom control, treating depression and improving social support, may contribute to reducing the desire for a hastened death in people with progressive

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[214] Somerville (n29) 5-6.

[215] I Illich, *Limits to Medicine. Medical Nemesis: The Expropriation of Health* (Penguin 1976) 210.

[216] R Kastenbaum, ‘Psychological death’ in L Pearson (ed), *Dying and Death: Current issues in the treatment of the dying person*. (Case Western Reserve University Press 1969).

[217] Seymour (n211) 692.

[218] S Timmermans, ‘Resuscitation technology in the emergency department: towards a dignified death’ (1998)20(2) Soc Health Illness 144,148.

[219] When a patient begins hospice care, the focus of treatment is on palliative care: V Cox, ‘The Hospice Concept: Dying as a Part of Living’ (1988) Nursing Homes and Senior Citizen Care 29,29-30. ‘[H]ospice is known as a philosophy of care; a medically oriented team approach to managing the pain and symptoms for individuals with a limited life expectancy.’: WL Wheeler, ‘Hospice Philosophy: An Alternative to Assisted Suicide’ (1993)20 Ohio N.U.L.Rev 755,755.

[220] ME Chopko & MF Moses, ‘Assisted Suicide: Still a Wonderful Life?’ (1995)70 Notre Dame Law.Rev. 519,531-32.

[221] M Hotopf et al, ‘Assisted suicide: why psychiatrists should engage in the debate (Editorial)’ (2011)198 Br J Psychiatry 83.

incurable illnesses.[222] In Seale's 2007-2008 survey on end-of-life care, 27% of doctors found their patients' desire for a hastened death to have reduced over time, with 21% thinking that this was in response to the care provided.[223] Further commentary on the ability to change one's desire for death can be seen in Hotopf et al's 2010 editorial comments on the role of psychiatrists in assisted suicides. They note that psychiatrists who see patients over long periods of time often find that their patients' distress and suicidality fluctuate.[224] Additionally, there is also the potential for patients to adapt to their terminal illness. As demonstrated in a 2005 study on depression and anxiety in women breast cancer sufferers, the researchers found that distress at the early stages of cancer often remitted as patients adapted to their illness.[225] This is often referred to as the 'response shift' phenomenon, and will be discussed further in Chapter Four.[226] Foreign studies such as Chochinov et al's 1995 American study also found that the desire for death among the terminally ill is inconsistent and changes over time. These researchers also observed that whilst a desire for death is strongly influenced by pain and depression, these are potentially reversible.[227]

As observed by Seale and Addington-Hall, a concern often raised by those campaigning for or against the legalisation of assisted death is that not all terminally ill patients have access to effective palliative care or hospices.[228] The validity of this concern was established by the 2011 Palliative Care Funding Review. The Review found that of approximately 470,000 people who die in England annually, an estimated 355,000 require some form of end-of-life care, with 92,000 having unmet specialist palliative needs.[229] This is supported by the 2005 report of the charity, Help the Aged, which stated that older persons (defined as over-75s) in England and Wales did not all have equal access to palliative care. Help the Aged found that older people in care homes were far less likely than others to access specialist palliative care, or be admitted to a

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[222] Price (ch1 n45).

[223] C Seale, 'Hastening death in end-of-life care: a survey of doctors' (2009)69(11) Soc Sci Med 1659.

[224] Hotopf (n221).

[225] C Burgess et al, 'Depression and anxiety in women with early breast cancer: five year observational cohort study' (2005)330 BMJ 702.

[226] See section 4.4.1 under *An objective professional evaluation*.

[227] Chochinov (ch1 n79) 1189-90.

[228] Seale and Addington-Hall (n32).

[229] T Hughes-Hallet et al, Palliative Care Funding Review, *Funding the Right Care and Support for Everyone: Creating a fair and transparent funding system; the final report of the Palliative Care Funding Review: an independent review for the Secretary of State for Health* (July 2011) 11.

hospice.[230] Higginson et al observe that overall, there is a general trend for the number of hospice deaths among older people to decrease as their age increases, while the numbers dying in care homes show a parallel increase.[231] It is argued that this lack of access to palliative care could make older people vulnerable under any law which permits assisted death. This concern is further exacerbated by the government's announcement in July 2013 to phase out the Liverpool Care Pathway for the Dying Patient ('LCP'), a UK care pathway, due to the abuse and misuse of its procedures by staff.[232] The LCP was designed to offer a peaceful death for elderly patients who are nearing the end of their lives.[233] It was developed to help doctors and nurses provide quality end-of-life care, and covers palliative care options for patients in the final days or hours of life.[234] Its end-of-life care includes the withdrawal or withholding of medication and food from incompetent patients.[235]

It is argued that although physicians may do everything medically possible to minimise the distress and discomfort of a terminally ill patient through palliative care,[236] terminal illness may involve intolerable pain and suffering that is beyond the scope of optimal palliative care. This possibility was challenged by the RCS in its written evidence to the 2010 Commission on Assisted Dying, when it stated that 'It is unusual to encounter a patient whose symptoms are truly unmanageable and greater availability of palliative care expertise would help this further'.[237] As Miller forcefully argued in 1992, although effective palliative care can reduce the demand for assisted death, it will not eliminate it completely.[238] This was also reflected in the message by the National Council for

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[230] Help the Aged, *Dying in Older Age: reflections and experiences from an older person's perspective* (T Owen ed, May 2005).

[231] IJ Higginson et al, 'Where do cancer patients die? Ten-year trends in the place of death of cancer patients in England' (1998)12 Palliative Medicine 353.

[232] The government review and its reports can be located at: Independent Review of the Liverpool Care Pathway, *More Care Less Pathway: A Review of the Liverpool Care Pathway* (15 July 2013) <www.gov.uk/government/publications/review-of-liverpool-care-pathway-for-dying-patients> accessed 30 August 2013. The LCP was originally developed by the Royal Liverpool University Hospital and the Marie Curie Hospice in Liverpool for the care of terminally ill cancer patients. The Marie Curie Palliative Care Institute Liverpool has overseen the development and dissemination of the LCP since then, and the LCP aims to ensure that uniformly good care is given to everyone, wherever they are – in hospitals, nursing homes, or in their own homes – when it is thought that they will die within hours or within two or three days.

[233] See H Saul, 'Liverpool Care Pathway: Controversial "end-of-life" regime for dying patients "to be replaced"' *The Independent* (London,13 July 2013).

[234] See the Marie Curie Palliative Care Institute, *Liverpool Care Pathway for the Dying Patient (LCP):Supporting care in the last hours or days of life: LCP Model Pathway UK Core Documentation* (October 2012).

[235] Saul (n233).

[236] ED Pellegrino, 'Compassion Needs Reason Too' (1993)270 JAMA 874,874.

[237] *Report of the Commission on Assisted Dying* (ch1 n51) 79.

[238] RJ Miller, 'Hospice Care as an Alternative to Euthanasia' (1992)20 Law,Med& Health Care 127,128.

Hospice and Specialist Palliative Care Services in 1997: ‘universal availability of excellent palliative care services will not and can never eliminate all such rational and persistent requests for [assisted death].’[239] Studies in the UK have also demonstrated that palliative care is not able to provide total relief for some patients. For example, a working group of the RCP in 2000 found that opioids could produce good pain control in only 80% of patients.[240] This was supported by further studies between 2000 and 2002 that found that pain control for some patients will remain inadequate even with pain control measures.[241] Inadequate pain control was also a concern under Oregon’s DDA. In its 2012 Annual Report, the OPHD found that 90.4% of terminally patients who died under the DDA between 1998 and 2012 received hospice care, but 23.5% of these patients had concerns about inadequate pain control.[242]

Singer and Siegler express concern that the legalisation of physician-assisted death would remove incentives for the medical profession to improve pain control, and provide adequate palliative care.[243] A lack of expertise in palliative care, and thus its inadequacy, was raised by Pollard in 2001 when he argued that, ‘Because virtually every survey of palliative care [in the UK] has revealed serious shortfalls in training and practice, it could never be assumed that care had always been adequate.’[244] Those against the legalisation of assisted death in England and Wales also argue that such a law would detract from the growing need for palliative care services.[245] To the contrary, as will be observed in Chapter Five, the physician-assisted suicide law in Oregon has had quite the opposite effect. The law has led to improved and better palliative care for patients requesting physician-assisted suicide. Ganzini et al’s survey on physicians’ attitudes in Oregon found that 30% of physicians increased their number of referrals to

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[239] The National Council for Palliative Care (NCPC) is the umbrella charity for all those involved in palliative, end of life and hospice care in England, Wales and Northern Ireland. See also: International Association for Hospice & Palliative Care, ‘Statements on Euthanasia and Physician Assisted Suicide’ <www.hospicecare.com/Ethics/statements.htm> accessed 18 June 2013.

[240] ‘Principles of pain control in palliative care for adults. Guidance prepared by a Working Group of the Ethical Issues in Medicine Committee of the Royal College of Physicians’, (2000)34(4) Journal of the Royal College of Physicians of London 350.

[241] J Davies and A McVicar, ‘Issues in effective pain control. From assessment to management (review)’ (2000)6(4) Int’l J Palliative Nursing 162; I Gilron et al, ‘Patients’ attitudes and prior treatments in neuropathic pain: a pilot study’ (2002)7(4) Pain Research and Management 199.

[242] OPHD, *Oregon’s Death with Dignity Act — 2012* (15th Annual Report).

[243] PA Singer & M Siegler, ‘Sounding Board: Euthanasia - A Critique’ (1990)322 N Engl J Med 1881,1883.

[244] BJ Pollard, ‘Can Euthanasia Be Safely Legalized?’ (2001)15 Palliative Medicine 61,63.

[245] Harris (ch1 n81).

hospice care, and 76% worked to increase their knowledge of pain medication.[246] Hospice nurses and social workers in Oregon have also noticed an increase in physicians' knowledge of palliative care, and in their willingness to refer patients to hospice care.[247]

In this thesis the view is taken that a law on physician-assisted suicide will not meet the needs of society if it operates against a backdrop of inadequate palliative care.[248] Under such circumstances, such a law may be viewed as a backlash against a medical profession which fails to address the needs of the terminally ill.[249] As Pollard rationally asserts, 'Even though good palliative care cannot always relieve all distressing symptoms, it would surely be wrong to propose [assisted death] for a terminally ill patient who had not received adequate medical and nursing care.'[250] It is submitted that with the legalisation of physician-assisted suicide, a contemporaneous development of palliative care should also be promoted in England and Wales. Rather than being considered as an alternative to assisted death, palliative care should be explored and exhausted before resorting to physician-assisted suicide as an option of last resort.[251] As with the assisted death laws of jurisdictions such as Belgium, Oregon (US) and the Northern Territory (Australia) (discussed in Chapter Five), the legalisation of physician-assisted suicide in England and Wales should require that palliative care options be explored (and possibly be exhausted) as a prerequisite to assisted suicide.

It is submitted that a physician's powers should not be limited to curing and treating, but should also include alleviating the suffering of those terminally ill patients who are beyond the reach of effective palliative care through physician-assisted suicide.[252] It is inhumane to force a terminally ill patient to continue a life of unbearable pain and suffering.[253] Since doctors are already legally permitted to withhold or withdraw life-

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[246] L Ganzini et al, 'Oregon Physicians' Attitudes About and Experiences with End-of-Life Care Since Passage of the Oregon Death with Dignity Act' (2001)285 JAMA 2363,2365.

[247] ER Goy et al, 'Oregon Hospice Nurses and Social Workers' Assessment of Physician Progress in Palliative Care Over the Past 5 Years' (2003)1 Palliative& Supportive Care 215,217.

[248] Keown (ch2 n389).

[249] DR Schanker, 'Of Suicide Machines, Euthanasia Legislation, and the Health Care Crisis' (1993) 68(3) Indiana LJ 977, 1009.

[250] Pollard (n244) 63.

[251] FG Miller & H Brody, 'Professional Integrity and Physician-Assisted Suicide' (1995)25(3) Hastings Cent.Rep 8.

[252] M Gunderson and D Mayo, 'Restricting Physician-Assisted Death to the Terminally Ill' (2000)30(6) Hastings Cent.Rep 17,18.

[253] See *Pretty* (ECtHR)(ch2 n22).

sustaining treatment from patients and allow them to die slowly,[254] it would be more compassionate and humane to assist a patient to end their life quickly by taking a lethal dose of medication.[255]

Those opposing the legalisation of assisted death believe that most terminally ill patients can experience a dignified death with palliative care.[256] Some commentators argue that the basic tenets of palliative care – 'relieving symptoms, enhancing control, and preserving dignity'[257] – constitute an overall goal of enabling patients to die with dignity.[258] Significantly, the BMA is also of the view that the continuing improvement in palliative care allows patients to die with dignity.[259] The issue of dying with dignity will be discussed in the following section.

3.4.4 *Concerns over patient dignity*

Although palliative care, as discussed above, may substantially reduce the pain and discomfort of grave illness, no amount of palliative care can address concerns regarding the loss of autonomy and control over bodily functions.[260] The inability to maintain control or independence while dying is regarded as a fundamental loss of dignity by the terminally ill.[261] This is demonstrated by a 2004 UK study on dignity in old age, which found that the elderly often associate dignity with autonomy, independence, and preserving one's intellectual powers.[262] Similarly, in Oregon, the 2012 Annual Report of the OPHD found that the end-of-life concerns of those requesting a physician-assisted suicide under the DDA between 1998 and 2012 were more commonly a loss of autonomy (91.2%), a decreasing ability to participate in activities that made life enjoyable (88.8%), the loss of dignity (82%), and the loss of control of bodily functions

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[254] See Bland's case (ch1 n12), *Burke* (ch2 n277), and *Re B (Adult: Refusal of Treatment)* (ch1 n42).

[255] AC Hall, 'To Die with Dignity: Comparing Physician Assisted Suicide in the United States, Japan and the Netherlands' (1996)74(3) Wash.U.L.Rev. 803,812.

[256] Clark (n157) 103.

[257] TE Quill, 'Death and Dignity: The Case of Diane' [a letter] (1991)325 N Engl J Med 658,660.

[258] M Abiven, 'Dying with dignity' (1991) 12 World Health Forum 375; TN Madan, 'Dying with dignity' (1992)35 Soc Sci Med 425.

[259] Pickover (n70). See also BMA, 'What is current BMA policy on assisted dying?' (n70).

[260] Harris (ch1 n81).

[261] HM Chochinov, 'Dignity-Conserving Care – A New Model for Palliative Care Helping the Patient Feel Valued' (2002)287(17) JAMA 2253.

[262] G Woolhead et al, 'Dignity in Older Age: What Do Older People in the United Kingdom Think?' (2004)33 Age and Ageing 165.

(51.6%).[263] Inadequate pain control was the main concern of a mere 23.5% of patients who died under the law.

A loss of dignity is also associated with fears of debility, loss of cognition, and dehumanisation from both the underlying illness, as well as the powerful effects of palliative medication.[264]Additionally, terminal degenerative conditions such as motor neurone disease[265] involve an inevitable tragic decline in physical integrity and functional ability, with patients enduring a life beyond what they perceive to be dignified bounds.[266] Thus, even with skilled end-of-life care,[267] terminally ill patients may experience a degree of suffering towards the end of life that they consider can only be relieved by ending their life at a time of their own choosing.[268] It is concluded that a quick and painless death would mean more to terminally ill patients, than being subjected to a prolonged and undignified dying process overcome by intolerable pain and suffering.[269] Again, consistent with previous argument, physician-assisted suicide, as an option of last resort, provides assurance to the terminally ill that they can reliably depend on physicians to achieve a peaceful and dignified death.[270]

3.4.5 *Concerns over a slippery slope*

According to Smith, slippery slope arguments posit that because accepting a certain desirable legal standard might lead to the subsequent acceptance of a standard that is 'undesirable', the desirable standard 'should not be accepted because it leads to the second, even if that is the only thing wrong with the first'.[271] Those opposed to the legalisation of physician-assisted suicide fear that it will start England and Wales down a slippery slope, firstly, towards the legalisation of voluntary euthanasia[272] and,

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[263] OPHD, 15th Annual Report (n242).

[264] Gostin (ch1 n68) 98.

[265] See *Pretty* (ECtHR)(ch2 n22).

[266] Harris (ch1 n81).

[267] For example, the LCP (see text to nn 232-235). However, the LCP will be abolished, following a government commissioned review that found its procedures to have been misused and abused. See: S Boseley, 'Liverpool care pathway for dying patients to be abolished after review' *The Guardian* (London,15 July 2013).

[268] Branthwaite (ch2 n395).

[269] CK Cassel & DE Meier, 'Morals and Moralism in the Debate Over Euthanasia and Assisted Suicide' (1990)323 N Engl J Med 750,751.

[270] Gostin (ch1 n68) 98-99.

[271] SW Smith, 'Evidence for the Practical Slippery Slope in the Debate on Physician-Assisted Suicide and Euthanasia' (2005)13 Med.L.Rev 17,17 fn2.

[272] 'Voluntary euthanasia' (ch1 n7).

secondly, towards vulnerable groups becoming 'targets of non-voluntary euthanasia[273] disguised as physician-assisted suicide'.[274] These slippery slope concerns are considered in detail in Chapter Six.

3.4.6 *Protecting the vulnerable*

Those opposed to the legalisation of assisted death often argue that certain groups of people in society would be vulnerable under such a law. Such vulnerable groups might be those who are depressed, feeling alone or isolated, feeling family or financial pressure, or feeling helpless due to a loss of control and independence.[275] Four categories of vulnerable people are discussed below. These are the depressed, those who find themselves to be a burden to others, the elderly[276] and the disabled.

– *The depressed*

Studies among the terminally ill have shown that depression is strongly associated with a request for assisted death. A 2000 study by Breitbart et al found that terminally ill patients with depression were four times more likely to request assisted death than those without.[277] A recent study by Price et al in 2010, on the desire for hastened death in a UK palliative population, found that an estimated 14% of the 300 terminally ill participants had a desire for a hastened death, out of which 63.6% were identified as having some form of depressive disorder.[278] In Ganzini et al's 2000 survey on the competence required to consent to an assisted suicide, the researchers found that of 290 psychiatrists in Oregon who responded to the survey, 58% (not a clear consensus) asserted that the presence of a major depressive disorder should result in an automatic finding of incompetence for the purposes of obtaining assisted suicide.[279] It is often argued that patients with treatable clinical depression have impaired competence to

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[273] 'Non-voluntary euthanasia' (text to ch1 n98).

[274] Pailet (ch1 n97) 66.

[275] D Azevedo, 'Assisted Suicide is Legal, Now What?' *Medical Economics* (11 May 1998), quoting Dr. Patrick Dunn, Chair of the Task Force on Caring for the Terminally Ill, in Portland, Oregon.

[276] As defined in section 3.2.3.

[277] W Breitbart et al, 'Depression, Hopelessness, and Desire for Hastened Death in Terminally Ill Patients with Cancer' (2000)284 JAMA 2907.

[278] Price (ch1 n45).

[279] L Ganzini et al, 'Evaluation of Competence to Consent to Assisted Suicide: Views of Forensic Psychiatrists' (2000)157 Am J Psychiatry 595.

request assisted death.[280] However, Levene and Parker's 2010 UK study on depression in euthanasia and assisted suicide, found that 'depression does not necessarily make patients incompetent and there is little evidence on whether treatment will be acceptable to patients at the end of life, or will change end-of-life decisions'.[281]

There have been conflicting studies on whether one's competence is necessarily affected by clinical depression. In a 1998 study of Oregonians with amyotrophic lateral sclerosis (a type of motor neurone disease), no association was found between depression and an intent to request a lethal prescription.[282] Some commentators argue that depression can impair patient autonomy, and yet coexist with a competent and autonomous wish for an assisted death.[283] For example, in a 1994 American study on the effect of depression treatment on elderly patients on life-sustaining treatment, Ganzini et al found that a patient suffering from clinical depression may still make an informed, competent and reasoned decision for an end-of-life decision, provided the depression is not distorting their judgement.[284] Similarly, Levene and Parker's study (discussed above) found that most people with major depression retain competence to make medical decisions, and that they did not rank depression as a motivating factor in their request for physician-assisted suicide.[285]

Nevertheless, it is accepted that clinical depression would most likely distort a patient's rational capacity to make choices.[286] Emanuel et al's 2000 American study of attitudes and desires related to euthanasia and physician-assisted suicide among terminally ill patients found that terminally ill patients who suffer from treatable depression are more likely to change their minds about ending their life than patients without depression.[287] Similarly, Ganzini et al's 2000 study found that a trial of antidepressant medication had

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[280] Y Conwell, ED Caine, 'Rational suicide and the right to die. Reality and myth' (1991)325(15) N Engl J Med 1100,1101-1102.

[281] I Levene and M Parker, 'Prevalence of depression in granted and refused requests for euthanasia and assisted suicide: a systematic review' (2011)37 J Medical Ethics 205,208.

[282] L Ganzini et al, 'Attitudes of Patients with Amyotrophic Lateral Sclerosis and Their Care Givers toward Assisted Suicide' (1998)339 N Engl J Med 967.

[283] S Block & A Billings, 'Patient Requests for Euthanasia and Assisted Suicide in Terminal Illness: The Role of the Psychiatrist' (1995)36 Psychosomatics 445.

[284] L Ganzini et al, 'The Effect of Depression Treatment on Elderly Patients' Preferences for Life-Sustaining Medical Therapy' (1994)151 Am J Psychiatry 1631,1634-35.

[285] Levene and Parker (n281) 208.

[286] RA Burt, 'Constitutionalizing Physician-Assisted Suicide: Will Lightning Strike Thrice?' (1997)35 Duq.L.Rev. 159,174.

[287] EJ Emanuel et al, 'Attitudes and Desires related to Euthanasia and Physician-Assisted Suicide among Terminally Ill Patients and their Care Givers' (2000)284(19) JAMA 2460.

altered the requests of 46% of patients who had sought a lethal prescription under Oregon's DDA.[288] This was also demonstrated in an earlier 1998 UK study on suicide and attempted suicide, where researchers found that once depression was treated effectively, around 99% of patients changed their mind about wanting to die.[289] Although the presence of depression does not necessarily mean that a patient's choice is irrational,[290] it is concluded that the reasoning processes of a depressed patient will generally be biased, and their capacity to make well-considered end-of-life decisions is likely to be affected.[291]

Studies show that physicians often fail to detect depression amongst terminally ill patients, with detection rates varying between 40% and 80%. As argued by Finlay, a terminally ill person can appear to have capacity when their decision making is in fact distorted by depression.[292] In 2006, Hicks noted in his literature review that, even when a 'low mood' is recognised in severely ill patients, physicians tend to consider it a normal and understandable reaction by the patient to their condition.[293] Chochinov made a similar observation that same year in a Canadian journal. He observed that as terminally ill patients frequently experience moments of sadness, depression is often overlooked.[294] Thompson et al's 2000 study on the detection of depression in primary care found that even British GPs who were trained in depression, recognised it in only 39% of all depressed patients attending their practices.[295] A subsequent Canadian study by Gruneir et al in 2005, however, had a higher rate of detecting depression in patients with advanced illness. Their study found that depression was undiagnosed in 20-30% of terminally ill patients.[296] Additionally, studies in the UK, between 2005 and 2006,

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[288] Ganzini (ch1 n78) 563.

[289] Hawton & Fagg, 'Suicide and other causes of death, following attempted suicide' (1998)152 Br J Psychiatry 359.

[290] Conwell and Caine (n280) 1101-1102.

[291] Burt (n286) 174.

[292] IG Finlay, 'Crossing the "bright line" – difficult decisions at the end of life' (2006) 6 Clinical Medicine 398.

[293] MHR Hicks, 'Physician-assisted suicide: a review of the literature concerning practical and clinical implications for UK doctors' (2006) 7(39) BMC Family Practice 10.

[294] HM Chochinov, 'Dying, Dignity, and New Horizons in Palliative End-of-Life Care' (2006)56 CA-Cancer J Clin 84.

[295] C Thompson et al, 'Effects of a clinical-practice guideline and practice based education on detection and outcome of depression in primary care: Hampshire Depression Project randomized controlled trial' (2000)355 Lancet 185.

[296] A Gruneir et al, 'Depression in patients with advanced illness: an examination of Ontario complex continuing care using the Minimum Data Set 2.0' (2005)3 Palliative and Support Care 99.

showed that the treatment of depression by GPs was limited by their skills and lack of resources.[297]

It is submitted that depression amongst patients is significantly overlooked and under-treated in England and Wales.[298] Terminally ill patients who are clinically depressed may be vulnerable if physician-assisted suicide were to be legalised.[299] As convincingly argued by Chochinov, physicians are often unable to recognise, assess and address the psychological distress that many terminally ill patients feel. Untreated depression, according to him, may increase a patient's burden of suffering and lead to a significant decline in quality of life. This may cause them to turn to physician-assisted suicide.[300] Thus, in order to meet the needs of these potentially vulnerable members of society, measures to ensure an effective mental health evaluation will need to be considered. Price et al observe in their 2010 study that a number of remedies available through palliative care which treat depression might reduce the desire for assisted death by those with terminal illness.[301] For this reason, palliative care is also recommended as part of any legalisation of assisted death.

– *Patients as a burden on others*

As noted by Hardwig, being a burden to loved ones is enough reason for some patients to want to end their lives. It is the fear of losing one's physical ability or intellectual capacity and being handed over to the will of others that makes them vulnerable to a law on assisted death.[302] Similarly, other commentators observe that patients may be indirectly encouraged or pressured by physicians, family members, and society to request death in order to spare their families financial or emotional strain.[303] Evidence from Oregon found that in 2000, 63% of patients who received physician-assisted suicide under Oregon's DDA had expressed a strong sense of being a significant burden

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[297] H Burroughs et al, '"Justifiable depression": how primary care professionals and patients view late-life depression? A qualitative study.' (2006)23(3) Family Practice 369. See also J Hyde et al, 'A qualitative study exploring how GPs decide to prescribe antidepressants' (2005)55 British Journal Gen Practice 755.

[298] DW Kissane, BJ Kelly, 'Demoralisation, depression and desire for death: problems with the Dutch guidelines for euthanasia of the mentally ill' (2000)34 Aust NZ J Psychiatry 325.

[299] Royal College of Psychiatrists, *Assisted Dying for the Terminally Ill Bill – Statement from the Royal College of Psychiatrists on Physician Assisted Suicide* (7 April 2006) sub-s 2.3.

[300] Chochinov (n294) 86.

[301] Price (ch1 n45).

[302] J Hardwig, 'Is There a Duty to Die?' (1997)27(2) Hastings Cent.Rep 34.

[303] C McPherson et al, 'Feeling Like a Burden to Others: A Systematic Review Focusing on the End of Life' (2007)21 Palliative Medicine 115. See also: K Parsons-Suhl et al, 'Losing One's Memory in Early Alzheimer's Disease' (2008)18 Quality Health Resources 31.

to their family, friends, or caregivers.[304] It is submitted that palliative care could assist such vulnerable patients as its scope includes the social aspects of the patient in achieving a sense of control, relieving burden and strengthening relationships with their loved ones.[305]

As will be discussed in the following sections, if physician-assisted suicide were to be legalised then the elderly and the disabled might feel that they have a duty to die to relieve their loved ones, carers and society in general of their care.

– *The elderly*[306]

There is evidence that many elderly members of society (whose demographic growth is discussed in section 3.2.3) currently face some form of abuse or discrimination in England and Wales. This has been found by numerous UK studies conducted in the last six years. A 2007 study on the abuse and neglect of older people[307] found that 4% were experiencing some form of abuse.[308] A later study in 2009 found that 8.6% of older people living in the community were experiencing some form of abuse, most commonly psychological abuse (4.1%) and neglect (2.8%).[309]

Inadequate care and support for older people at the end of their lives was also documented in the 2011 'Report of the Health Service Ombudsman on ten investigations into NHS care of older people' ('2011 Ombudsman's Report'). The report criticised NHS staff for treating elderly people without compassion, and for condemning many to die in unnecessary pain, indignity and distress.[310] In 2011, the Care Quality Commission ('CQC') also published a report on the dignity and nutrition of older people being treated in NHS hospital trusts[311]. Approximately one in five of the hospitals visited were providing a level of care that 'posed risks to people's health and

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[304] AD Sullivan et al, 'Legalized physician-assisted suicide in Oregon' (2001)344 N Engl J Med 605.

[305] PA Singer et al, 'Quality end-of-life care: patients' perspectives' (1999)281 JAMA 163.

[306] As defined in section 3.2.3.

[307] As defined in section 3.4.3.

[308] Action on Elder Abuse, *Briefing Paper: The UK Study of Abuse and Neglect of Older People 2007*.

[309] King's College London & National Centre for Social Research, S Biggs et al, *Abuse and Neglect of Older People: Secondary Analysis of UK Prevalence Study* (PANICOA Research Initiative: Prevention of Abuse and Neglect in the Institutional Care of Older Adults,2009).

[310] Parliamentary and Health Service Ombudsman, *Care and Compassion? Report of the Health Service Ombudsman on ten investigations into NHS care of older people* (February 2011).

[311] Also known as an acute trust; it provides secondary health services within the National Health Service in the UK.

wellbeing'.[312] The findings of the 2011 Ombudsman's Report and the CQC's Report, published in February and October 2011 respectively, were further supported by the findings of the February 2013 *Report of the Mid Staffordshire NHS Foundation Trust Public Inquiry* ('*2013 Mid Staffordshire Report*').[313] As observed by Dame Christine Beasley (former Chief Nursing Officer for England) in the *2013 Mid Staffordshire Report*:

> I think we still have a real challenge in hospital care around the complex needs of our most vulnerable patients, which tend to be older people with a lot of complex conditions and who are normally, not exclusively, but who are normally in medical wards … that area … is still very challenging for us all, and I don't think we've got it right.[314]

It is argued that such existing circumstances may already constitute indirect pressure on elderly people in society to desire an assisted death. As noted in section 3.4.3, the concern that older members of society in England and Wales will be vulnerable to the legalisation of assisted death is further reinforced by the 2005 report by the charity, Help the Aged.[315] The Report stated that the opportunity to go into a hospice declined with age.[316] It showed that only 8.5% of older people who die of cancer do so in a hospice, compared with 20% of all those with cancer.[317] This has given rise to the description of older people as 'the disadvantaged dying'.[318]

Despite the adverse findings of the above mentioned reports, Seale's 2007-2008 survey of physicians on hastening death in end-of-life care found no statistical evidence that older patients are at a greater risk of end-of-life medical decisions which hasten death.[319] It is accepted that Seale's results provide no support for concerns that the elderly may be vulnerable if physician-assisted suicide were to be legalised in England and Wales.

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[312] Care Quality Commission, *Dignity and nutrition inspection programme: national overview* (October 2011).

[313] The Mid Staffordshire NHS Foundation Trust Public Enquiry, 'Final Report' (6 February 2013).

[314] The Mid Staffordshire NHS Foundation Trust Public Enquiry, *Report of the Mid Staffordshire NHS Foundation Trust Public Inquiry – Volume 2: Analysis of evidence and lessons learned (part 2)* para19.69.

[315] Refer text to n230.

[316] Help the Aged, *Dying in Older Age* (n230).

[317] ibid 34.

[318] L Harris, 'Continuing care: the disadvantaged dying' (1990)86(22) Nursing Times 26.

[319] Seale (n223).

Nevertheless, a law on physician-assisted suicide would have to address the present prejudices towards older members of society.[320]

– *The disabled*

There is also concern about the impact of legalising physician-assisted suicide on disabled members of society. Harris et al argue that such a law may encourage a societal view that suffering is senseless, that interdependency is a burden, and thus the lives of disabled people are not worth living.[321] Disability rights campaigners in England and Wales argue that in a society where disabled people are already not treated as equal citizens, a 'right to die' would endanger disabled people's right to live and their right to have their lives seen as being of equal value.

Not Dead Yet UK, a network of disabled people in the UK who oppose 'the legalised killing of disabled people', believes that legalising assisted death will inevitably lead to increasingly adverse beliefs about the quality of life of disabled people.[322] It reiterates Harris et al's concerns by stating on its website, 'If we give in to the demand to assist in a suicide we are reinforcing attitudes that say that the lives of disabled people are not worth living – that they are a particular burden to themselves, their relatives and friends, and the state.'[323] In March 2011, Scope, a UK disability charity, conducted a poll to explore disabled people's perspectives on assisted suicide.[324] 53% of respondents said they would be concerned about a change in the law to legalise assisted suicide. If assisted suicide was to be legalised, 35% of respondents expressed concern of pressure being placed on them to end their life prematurely, 70% expressed concern of pressure being placed on other disabled people to end their lives prematurely, and 56% believed it would be detrimental to the way that disabled people are viewed by society as a whole.

Similarly, the results of general opinion polls in the UK reflect a societal concern about the potential impact of extending the option for assisted death to those who might feel that their lives are devalued in the eyes of society, by the very fact that such an option is

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[320] RN Butler, MI Lewis, *Aging and mental health: positive psychosocial and biomedical approaches* (3rd edn, CV Mosby 1982).

[321] Harris (ch1 n81).

[322] Not Dead Yet UK (ch1 n93).

[323] See 'Not Dead Yet UK campaign' <www.notdeadyetuk.org> accessed 19 June 2014.

[324] ComRes, 'Scope NDPP Survey February-March 2011'.

available.[325] As noted in Chapter One, the *23rd BSA Report* in 2007,[326] and the *26th BSA Report* in 2010,[327] found that only 45% support assisted dying for those with non-terminal conditions. The July 2009 Populus poll for *The Times* newspaper found that only 48% of respondents who supported assisted suicide under certain circumstances were in favour of extending this to people with a 'severe physical disability' who were otherwise healthy.[328] It is argued that any law which legalises physician-assisted suicide would have to contain strict safeguards to protect these members of society against any abuse of the law. Such safeguards are addressed in Chapter Seven.

3.4.7 *The laws on assisted death of other jurisdictions*

The laws of other jurisdictions which have permitted assisted death in some form (discussed in Chapter Five) have influenced English law in two respects. Firstly, they provide a source of knowledge which has informed and shaped the current debate on possible law reform.[329] Secondly, British citizens are able to obtain suicide assistance in more liberal jurisdictions – especially Switzerland. As the Swiss laws which permit assisted suicide are not restricted to Swiss residents, the Swiss right-to-die organisation, Dignitas, has become the most popular destination for British citizens seeking an assisted death abroad. By assisting death for so-called 'suicide tourists', these other jurisdictions are both encouraging calls for reform to current English laws, as well as generating complaints that current English laws are not being coherently prosecuted to prevent such suicide tourism from occurring.[330]

The laws of other jurisdictions have also heightened general public awareness of issues concerning assisted death, especially through the media coverage given to suicide tourism cases.

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[325] *Report of the Commission on Assisted Dying* (ch1 n51) 292.

[326] Clery et al (ch1 n61) 35-54.

[327] McAndrew (ch1 n70) 87-113.

[328] 'The Times Poll: July 17th-19th 2009' (ch1 n62).

[329] Lord Joffe's ADTI Bill 2004 (ch1 n48) was based on Oregon's DDA. See section 2.4.2.

[330] S Doughty, 'Has assisted suicide been legalised by stealth? 44 cases escape prosecution', *Daily Mail* (London, 6 September 2011).

3.4.8 *Media coverage*

The increasing media coverage given to the assisted suicides of Britons at Dignitas, and of high-profile court cases like those involving Debbie Purdy[331] and Tony Nicklinson,[332] has not only fuelled the debate on assisted death in England and Wales, but evoked huge public sympathy for those wanting assisted death to be legalised.[333] Some recent documentaries are highlighted below.

In December 2008, the television programme *Sky Real Lives* aired the documentary '*Right to Die*', about the assisted suicide of Craig Ewert at Dignitas in 2006.[334] The documentary covered the last four days of Ewert's life, and showed him dying with his wife at his side.[335] In 2009, a film called '*A Short Stay in Switzerland*', inspired by the life and death of Dr Anne Turner was produced by the British Broadcasting Corporation ('BBC').[336] Turner died at Dignitas in 2006, accompanied by her three children. In 2011, the British author, Sir Terry Pratchett, took part in a BBC documentary which followed the final days of a 71-year-old British man who travelled to Dignitas to die.[337] The documentary, called '*Choosing to Die*', was centred on Pratchett's belief in a right to take his own life.[338] There was also tremendous publicity surrounding Reginald Crews' death in 2003.[339] Crew was the first Briton to be publicly named as using the services of Dignitas.[340] In the hope of promoting the legalisation of assisted suicide, Crew was

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[331] *Purdy* (HL)(ch1 n31). See also A Hirsh, 'Debbie Purdy wins "significant legal victory" on assisted suicide' *The Guardian* (London,31 July 2009).

[332] S Boseley, 'Tony Nicklinson: fight to die with dignity "will not be forgotten"', *The Guardian* (London,23 August 2012).

[333] P Saunders, 'The Role of the Media in Shaping the UK Debate on "Assisted Dying"' (2011)11(3) Med.Law.Int'l 239.

[334] Ewert was a 59-year-old retired university professor who suffered from motor neurone disease.

[335] T Moore, 'Death was His Logical Choice' (*Sky News*, 10 December 2008) <http://news.sky.com/story/655023/death-was-his-logical-choice> accessed 3 September 2013.

[336] Turner had an incurable brain disease, progressive supranuclear palsy. She had seen her husband die from a closely related degenerative illness, and wanted to avoid the 'long, slow demise' that he had suffered. She believed it was 'everybody's right' to be able to 'die with dignity'. See R Savill, 'By the time you read this, I will be dead' *The Telegraph* (London,25 January 2006).

[337] The documentary filmed 71-year-old British millionaire Peter Smedley ending his life at Dignitas, in the presence of his wife.

[338] Pratchett, who was diagnosed with Alzheimer's in 2008, is himself a supporter of assisted death.

[339] Crew was terminally ill with motor neurone disease. See 'No charges over assisted suicide' (*BBC News*,9 April 2003) <http://news.bbc.co.uk/1/hi/england/merseyside/2933589.stm> accessed 19 June 2014.

[340] D Campbell, 'Non-medical right-to-die organisations' *The Guardian* (London,21 June 2009).

accompanied to Switzerland by not only his wife, but by a television documentary crew from ITV1.[341]

By giving the debate on the legalisation of assisted death in England and Wales such a high level of exposure, the media has not only helped shape the debate, but its coverage of suicide tourism cases has created a 'vicious cycle' in which greater public awareness of suicide tourism has encouraged greater numbers of people to pursue this option with news of this trend then receiving further media coverage.

3.5 Conclusion

The chapter examined the social, ethical and other influences affecting the development of the current law on assisted death in England and Wales. The influences examined were (i) religion, (ii) individualism, (ii) an aging population, (iv) sanctity of life, (v) self-determination, (vi) professional ethics, (vii) the four principles of medical ethics (respect for autonomy, non-maleficence, beneficence, and justice in medical care), (viii) consequentialism and deontology, (ix) the doctrine of double effect, (x) quality of life, (xi) paternalism, (xii) scarcity of healthcare resources, (xiii) public trust in physicians, (xiv) advances in medical technology, (xv) palliative care, (xvi) concerns over patient dignity, (xvii) concerns over a slippery slope, (xviii) protecting the vulnerable, (xix) the laws on assisted death in other jurisdictions, and (xx) media coverage. From an analysis of these influences, this chapter concludes that the current law is unsatisfactory, and that it fails to meet the needs of those seeking an assisted death. The reasons for this, are as follows.

Firstly, whilst the ethical influence of 'sanctity of life' may provide moral coherence to the current illegality of assisted death, this doctrine is upheld by neither the end-of-life medical decisions which are currently permitted, nor by the law which decriminalises suicide. The current level of public trust in the medical profession is one which exists despite physicians regularly making end-of-life medical decisions which hasten death. The chapter accordingly concludes that the legalisation of physician-assisted suicide would not undermine the integrity of the medical profession. Opposition by the GMC and BMA to the legalisation of physician-assisted suicide on these grounds is similarly unfounded, and is inconsistent with their own support for such end-of-life medical decisions which indirectly hasten death.

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[341] J Laurance, 'Terminally ill man's journey to Switzerland to find dignity - and death' *The Independent* (London,21 January 2003).

Secondly, the chapter demonstrated that other ethical influences are growing in England and Wales, and are now challenging the moral coherence of the current prohibition on assisted death. These include self-determination, quality of life, patient dignity, and the medical ethical principle of autonomy. As these influences continue to make the withdrawal or withholding of life-sustaining treatment more morally acceptable, the current prohibition on assisted death for those who competently request it tends to become more questionable.

Thirdly, whilst seldom articulated in public debate, the chapter also found that the medical ethical principle of ‘justice in medical care’ (which provides that medical care is to be distributed fairly to all patients), combined with the increasing scarcity of healthcare resources (encouraging efforts to save limited healthcare resources for their most beneficial uses), tend to make end-of-life medical decisions such as the withdrawal or withholding of life-sustaining treatment from patients more morally acceptable. This, combined with advances in medical technology that merely prolong the dying process of a patient, further strengthens the moral argument in favour of allowing assisted death with appropriate safeguards.

This chapter considered the vulnerable groups within society, including those who are depressed, those who regard themselves to be a burden on others, and the elderly. In its analysis of the need to protect these vulnerable groups, the chapter concluded that this need has strongly influenced current laws, and is currently well satisfied. However, if physician-assisted suicide were to be legalised, the potential for alternative safeguards to protect such vulnerable groups was also noted. These include mental health evaluations and adequate access to palliative care for those requesting an assisted death.

The chapter found that social influences such as religion, where there is now a strong trend towards secularisation, should no longer be relied upon to justify the current prohibition on assisted death. Further, the trend towards individualism in England and Wales is a social influence which supports autonomy and self-determination.

Increased public awareness of the legality of assisted death in other jurisdictions, due to the media coverage of the ‘suicide tourists’ who travel abroad to end their life, has in turn raised interest in changing the current law on assisted death in England and Wales due to a perception that it does not meet the needs of either society, nor of those seeking an assisted death.

A key ethical influence considered by this chapter was ‘quality of life’. It is argued in this thesis that a competent terminally ill patient should be able to obtain an assisted death, based upon their own decision of the point at which their quality of life is so poor as to be unbearable and unacceptable. This issue will be examined fully in the following chapter.

Chapter 4: Quality of Life

4.1 Introduction

Having considered the social and ethical context of the law on assisted death[1] in England and Wales in Chapter Three, this chapter will examine the extent to which 'quality of life'[2] has been considered in legally permitted end-of-life medical decisions.

The chapter will demonstrate that the withdrawal or withholding of life-sustaining treatment from incompetent patients is often influenced by a judgement of the patient's quality of life. As will be illustrated, such quality of life judgements are made under the guise of a 'best interests' assessment. The chapter seeks to establish that when allowing such withdrawal of treatment from incompetent patients, the English courts have decided cases based purely on the quality of life of patients. An examination of such end-of-life decisions involving infants is included in this chapter to further exemplify that the English courts have focused on a patient's 'quality of life' in their judgments.

The definition of 'quality of life' will be examined from a subjective patient perspective and from an objective professional perspective. The scope of quality of life in terms of health-related issues and in a much wider global sense will also be analysed in this chapter. The chapter seeks to establish that a competent patient who is terminally ill should be allowed to make a request for physician-assisted suicide based on a subjective evaluation of their quality of life[3] – a quality of life which they determine to be poor and unacceptable due to the unbearable suffering caused by their terminal illness. The chapter also seeks to establish that quality of life for purposes of law reform should be based on a subjective patient evaluation of health-related issues. The difficulties of using subjective measurement instruments to assess a terminally ill patient's quality of life will also be examined.

The following section will show that individuals seeking to end their lives do so based on a personal assessment of their quality of life. This is demonstrated not only by

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[1] 'Assisted death', defined in section 1.1.

[2] Quality of life is an ethical influence on the debate for the legalisation of assisted death, discussed in section 3.3.7.

[3] This would be in line with the House of Lords decision in *Purdy* where it was held that the right to private life under art 8(1) of the ECHR protects an individual's right to make autonomous choices regarding their quality of life, including the choice to end their life: *Purdy* (HL)(ch1 n31)[39].

assisted suicide cases at right-to-die organisations abroad, but also by cases where patients have requested the removal of life-sustaining treatment.

4.2 Competent patients – a question of quality of life

Britons who have ended their lives at the Swiss right-to-die organisation, Dignitas, include those suffering from a wide range of medical conditions, from the terminally ill with cancer,[4] motor neurone disease,[5] or progressive supranuclear palsy (a degenerative brain disease),[6] to those with progressive non-fatal conditions like multiple sclerosis,[7] and even to those with severe non-fatal conditions like spinal cord injuries.[8] In 2011, 84-year-old Nan Maitland, suffering from arthritis, ended her life at Dignitas simply because she wished to escape the 'long period of decline, sometimes called "prolonged dwindling", that so many people unfortunately experience before they die'.[9] In May 2013, an 83-year-old man chose to die at Dignitas because he did not want to face the agony of progressive dementia.[10]

As observed in Chapter Two, Baroness Hale in the case of *Purdy* noted that 'autonomous[11] individuals have different views about what makes their lives worth living'.[12] This situation is illustrated in the case of *Re B*,[13] where Ms B who was paralysed from the neck down, requested that her life-sustaining ventilator be switched off. Dame Elizabeth Butler-Sloss held that continued treatment was unlawful in the face of Ms B's competent refusal for treatment:

> If mental capacity is not in issue and the patient, having been given the relevant information and offered the available options, chooses to refuse the

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[4] H de Quetteville, 'Why I took my wife to die at Dignitas' *The Telegraph* (London,19 July 2009).

[5] Laurance (ch3 n341).

[6] A Thompson, '"Anne, if you drink this you will die": Why we stood by and allowed our mother to commit suicide' *Daily Mail* (London,18 January 2009).

[7] 'Assisted suicide: British multiple sclerosis sufferer ends life at Swiss "suicide clinic" Dignitas' *The Telegraph* (London,30 December 2010).

[8] Edwards (ch1 n21).

[9] Adetunji (ch1 n23).

[10] J Stevens, 'Man, 83, becomes first Briton to choose Dignitas assisted suicide because he had dementia' *The Daily Mail* (London,30 May 2013).

[11] See section 3.3.4.

[12] *Purdy* (HL)(ch1 n31) [66].

[13] *Re B (Adult: Refusal of Treatment*) (ch1 n42).

> treatment, that decision has to be respected by the doctors.[14]

Nevertheless, Keown persuasively argues that Ms B's assessment of her quality of life was significant to her decision to refuse life-sustaining treatment.[15] Ms B had been aware of the poor quality of life offered by the continuation of treatment. She said:

> Given the range of choices, I would want to recover and have my life back, or significant enough recovery to have a better quality of life. I am not convinced from the evidence that that is going to happen, and I find the idea of living like this intolerable.[16]

The influence of 'quality of life' was also apparent in Butler-Sloss' judgment:

> One must allow for those as severely disabled as Ms B, for some of whom life in that condition may be worse than death. It is a question of values and, as [expert healthcare professionals] have pointed out, we have to try inadequately to put ourselves into the position of the gravely disabled person and respect the subjective character of experience.[17]

Although the various medical conditions described above affect the quality of life of a person, the proposal for law reform in this thesis will be restricted to patients with a terminal illness. A legal medical option of physician-assisted suicide for those experiencing a poor and unacceptable quality of life due to a terminal illness will be discussed in detail in Chapter Seven. The cases examined in the following section will show that when allowing life-sustaining treatment to be withdrawn or withheld from incompetent patients, English courts have effectively been making judgements on a patient's quality of life. It will be demonstrated that the courts do this under the guise of acting in a patient's 'best interests'. This will be evidence that the English courts are used to making judgements on a patient's quality of life when determining end-of-life medical decisions.

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[14] ibid 474.

[15] Keown (ch2 n247).

[16] *Re B (Adult: Refusal of Treatment)* (ch1 n42) 461.

[17] ibid 472.

4.3 Incompetent patients – a question of quality of life

Before proceeding with an analysis of English cases involving incompetent patients, the scope of 'best interests' at common law will be briefly considered. This will establish what factors the courts have taken into account when assessing an incompetent patient's best interests, and accordingly in judging their quality of life.

At first, 'best interests' were assessed by courts solely in terms of medical interests. This was established in the 1990 case of *Re F*, which held that an assessment of 'best interests' was to be carried out by physicians using their professional medical judgement in accordance with a responsible body of medical opinion (i.e. the *Bolam* test).[18] However, in 2000, Thorpe LJ in *Re S (Adult Patient: Sterilisation)* held that:

> the *Bolam* test is applied only at the outset…In deciding what is best for the disabled patient the judge must have regard to the patient's welfare as paramount consideration. That embraces issues far wider than the medical.[19]

Similarly, in 2000, Butler-Sloss P in *Re A (Medical Treatment: Male Sterilisation)* not only separated the assessment of best interests from the *Bolam* test, but held that 'best interests encompasses medical, emotional and all other welfare issues'.[20] On appeal to the Court of Appeal, Thorpe LJ then developed an approach where a balancing exercise is applied to provide an objective welfare appraisal within which all factors deemed relevant to the decision are outlined and weighed, including factors based on subjective evidence, to ascertain a patient's best interests.[21] He proposed that a balance sheet should be drawn up, setting out on each side the actual advantages and disadvantages associated with continuing or discontinuing the treatment in question.[22] Thorpe LJ's 'objective welfare appraisal' was subsequently endorsed by Butler-Sloss LJ in the 2003 case of *Simms v Simms*, where she held:

> In my judgement, I have to assess the best interests in the widest possible way to include the medical and non-medical benefits and disadvantages, the

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[18] *Re F (Mental Patient: Sterilisation)* [1990] 2 AC 1. The *Bolam* test was set out in *Bolam v Friern Barnet Hospital Management Committee* [1957] 2 All ER 118.

[19] *Re S (Sterilisation: patient's best interests)* [2000] 2 FLR 389,403.

[20] *Re A (Medical Treatment: Male Sterilisation)* [2000] 1 FCR 193,200–201.

[21] MC Dunn et al, 'Constructing and Reconstructing "Best Interests": An Interpretative Examination of Substitute Decision-making under the Mental Capacity Act' (2007)29(2) J.Soc.Wel.& Fam.L. 117,125.

[22] *Re A (Male Sterilisation)* (n20) 206.

> broader welfare issues of the…[patient]…All of these matters have to be weighed up and balanced in order for the court to come to a decision in the exercise of its discretion.[23]

An examination of other common law cases will now follow. The following two sections will show that in judging the quality of life of newborn babies and mentally disabled adult patients, the English courts have emphasised that subjective measures of quality of life are essential to a ‘best interests’ assessment.

4.3.1 *Critically ill and severely disabled newborn babies*

In this thesis, it is argued that English courts have made quality of life judgements when allowing the withholding or withdrawal of life-sustaining treatment from children. This is evident from the judgment of Lord Donaldson in the 1990 case of *Re J*:

> There is without doubt a very strong presumption in favour of a course of action which will prolong life, but…it is not irrebuttable…Account has to be taken of the pain and suffering and quality of life which the child will experience if life is prolonged. Account has also to be taken of the pain and suffering involved in the proposed treatment itself.[24]

Thus, where a child is experiencing poor quality of life with life-sustaining treatment, and if such treatment is burdensome to them, in such cases Lord Donaldson has taken the view that the doctrine of sanctity of life[25] is no longer absolute.

In the 1990 case of *Re B (A Minor),* the court was confronted with parents who refused to consent to an urgent surgery for their newborn child.[26] The child was born with Down Syndrome and had an intestinal blockage which required immediate surgery. Due to the Down Syndrome, the parents were of the view that it would be better for the child to be allowed to die. Contrary to the parents’ view, the court held that it was in the best interests of the child to receive the operation. The focus of Templeman LJ and

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[23] *Simms v Simms* (2003) 1 All ER 669 [60].

[24] In *Re J (A Minor)* (ch2 n236) 938.

[25] See section 3.3.1.

[26] *Re B (A Minor) (Wardship: Medical Treatment)* [1990] 3 All ER 927 CA.

Dunn LJ’s judgments were on the child’s quality of life. Templeman LJ’s assessment of the child’s quality of life centred on:

> Whether the life of the child is demonstrably going to be so awful that in effect the child must be condemned to die, or whether the life of this child is still so imponderable that it would be wrong for her to be condemned to die.[27]

He noted that should the operation be carried out, the child would be able to lead a normal, relatively happy life, to such extent as could be expected of any child with Down Syndrome. Dunn LJ’s quality of life assessment focused on the intolerability of the child’s life. He said, ‘there is no evidence that this child’s short life is likely to be an intolerable one. There is no evidence at all as to the quality of life which the child may expect.’[28] It is argued that the Court of Appeal in *Re B (A Minor)* made a paternalistic[29] judgement of the child’s quality of life. The Court would have most likely relied on the medical assessments of doctors in making its quality of life judgement and allowing the operation to take place.[30]

As with Dunn LJ’s judgment in *Re B (A Minor)* noted above, the focus of Taylor LJ’s ‘quality of life’ judgment in *Re J*[31] (noted above) was ‘intolerability’. In *Re J*, a child had been born prematurely, and was suffering from severe brain damage and epilepsy. It was likely that the child would be deaf and blind, possess not even limited intellectual abilities, and would develop serious quadriplegia. The Court of Appeal had to decide whether the child should be ventilated, if its breathing were ever to cease. The Court held that where the deformities of a newly born infant – when viewed from the perspective of a person able to make a sound judgement – were such that life would be intolerable, then life-preserving ventilation could lawfully be withheld.[32] However, bearing in mind the child’s ‘best interests’, the Court emphasised the need to judge

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[27] ibid 929.

[28] ibid 930.

[29] See section 3.3.8.

[30] B Wright et al, ‘Clinical dilemmas in children with life-limiting illnesses: decision making and the law’ (2009)23 Palliative Medicine 238,246.

[31] *Re J (A Minor)* (ch2 n236).

[32] ibid.

quality of life from the child's perspective. Taylor LJ attempted to determine the child's 'assumed' view by applying the 'substituted judgement' standard:[33]

> the court [should] judge the quality of life the child would have to endure if given the treatment and decide whether in all the circumstances such a life would be so afflicted as to be intolerable to that child…the test should not be whether the life would be intolerable to the decider. The test must be whether the child in question, if capable of exercising sound judgment, would consider the life tolerable.[34]

The Court of Appeal in *Re J* accepted that disabled children may gain pleasure and satisfaction from a quality of life that seems intolerable to others.[35] It is submitted that by emphasising the need to judge quality of life from the child's perspective, Taylor LJ had stressed a need to respect patient autonomy[36] in such cases.

It is argued that there are real difficulties in applying the 'substituted judgement' standard to newborn babies. Forming a substituted judgement for a newborn baby is speculative, as it is impossible to know what a newborn baby would think of their likely quality of life and what they would prefer. Where medical decisions for incompetent adult patients are guided by the 'substituted judgement' standard, the courts are often able to assess a patient's 'best interests' based on the patient's known beliefs, preferences, views, and wishes from when they were competent. As appropriately observed by Rhoden, the 'substituted judgement' standard is ideal for patients who have previously expressed their views and is also feasible for patients who never expressed their views but whose established personalities provide clues as to their probable desires. However, this is an exercise in futility for infants or for patients with profound retardation who have never developed desires and preferences.[37] As Brazier argues, 'substituted judgement' in the case of incompetent patients can only ever become an integral part of 'best interests' where such judgement can be discerned.[38] Further, the 'substituted judgement' standard also does not take into account the 'response shift'

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[33] See section 2.3.3 under *Best interests*.

[34] In *Re J (A Minor)* (ch2 n236) 945.

[35] ibid 936, 938 (Lord Donaldson).

[36] See section 3.3.4.

[37] NK Rhoden, 'Treatment Dilemmas for Imperiled Newborns: Why Quality of Life Counts' (1985)58 Southern Calif.L.Rev 1283,1304.

[38] Brazier (ch2 n268)132.

phenomenon,[39] i.e. the possibility of a newborn infant adapting to their condition. It is submitted that an assessment of 'best interests' based on a child's assumed view of their quality of life would be a wholly speculative exercise by the courts. In such situations, the courts would most likely rely on medical assessments, and make a paternalistic judgement of a child's quality of life.

In the cases of *Re B (A Minor)*[40] and *Re J*[41] discussed above, the English courts determined the 'best interests' of the newborn infants by relying on medical assessments provided by doctors. Nevertheless, some commentators argue that the 'best interests' standard involves a consideration of non-medical matters as well, for which physicians are not qualified to be the arbiters.[42] Such a wider 'best interests' standard was accepted by the Court of Appeal in the 2005 case of Charlotte Wyatt, below.[43]

In *Wyatt*, Charlotte Wyatt was a severely disabled two-year-old child, who was born prematurely with chronic respiratory and kidney problems coupled with severe brain damage that left her blind, deaf and incapable of movement.[44] Charlotte's physicians felt that further aggressive treatment in the event of respiratory collapse would not be in her 'best interests'. Due to Charlotte's short life expectancy of only a few months, and her quality of life that could not be improved, the High Court ruled in favour of her physicians.[45] This was contrary to the wishes of Charlotte's parents. The High Court decision, which was clearly dependent on the 'best interests' assessment by Charlotte's doctors, was reviewed by the Court of Appeal after Charlotte survived longer than expected. Although still profoundly ill, Charlotte's condition and quality of life had improved. The 'do not resuscitate' order which was initially imposed by the High Court, was ordered to be removed. The Court of Appeal took the view that where parents and physicians cannot agree on the termination or prolongation of life-sustaining treatment concerning a child, the courts have a duty to make an objective and independent decision in the child's 'best interests' but from the child's viewpoint.[46] The Court of Appeal referred to Thorpe LJ's approach in *Re A (Medical Treatment: Male*

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[39] See section 3.4.3.

[40] *Re B (A Minor)* (n26).

[41] *Re J (A Minor)* (ch2 n236).

[42] M Charlesworth, *Bioethics in a Liberal Society* (CUP 1993) 51.

[43] *Wyatt v Portsmouth Hospital NHS Trust* [2005] EWCA 1181.

[44] *Wyatt v Portsmouth Hospital NHS Trust (No 3)* [2005] EWHC 693 (Fam).

[45] ibid [16].

[46] *Wyatt* (CA)(n43)[91].

Sterilisation)[47] (discussed above) and endorsed the 'objective welfare appraisal'. The Court emphasised that there is a presumption in favour of 'sanctity of life' but that it is not absolute and may be rebutted:

> The welfare of the child is paramount, and the judge must look at the question of the child's welfare from the assumed point of view of the patient…There is a strong presumption in favour of a course of action which will prolong life, but the presumption is not irrebuttable…The term 'best interests' encompasses medical, emotional and all other welfare issues…The court must conduct a balancing exercise in which all the relevant factors are weighed…and a helpful way of undertaking this exercise is to draw up a balance sheet…the court must…balance all the conflicting considerations in a particular case and see where the final balance of the best interests lies…to strike the balance between benefit and harm.[48]

Thus, based on the 2005 Court of Appeal decision in *Wyatt,* the assessment of a child's 'best interests' is an 'objective welfare appraisal', that focuses on a child's subjective assessment of their own welfare, and is entirely focused on fostering an outcome that maximises the child's welfare.[49]

It is submitted that by applying the 'objective welfare appraisal' approach, and thus by conducting a balancing exercise, the court would effectively be making a paternalistic judgement as to what would be considered a benefit or harm to a child. The court acts as the child's proxy in determining the child's welfare. The objective welfare appraisal approach incorporates an element of subjectivity based on available evidence. However, as mentioned earlier, this is impractical for children like Charlotte who, due to infancy or profound retardation, have never developed desires and preferences. Thus, rather than promoting the autonomy of a child, the 'objective welfare appraisal' approach would amount to the court making a paternalistic judgement of a child's quality of life.

In conclusion, the cases of *Re J*[50] and *Wyatt*[51] demonstrate that the English courts have incorporated subjective interests into an objective framework within which a person's

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[47] *Re A (Male Sterilisation)* (n20) 206.

[48] *Wyatt* (CA)(n43)[87]-[90].

[49] Dunn (n21) 131.

[50] *Re J (A Minor)* (ch2 n236).

overall 'best interests' is determined.[52] In doing so, the courts are placing some emphasis on patient autonomy, even though decisions are being made by others on their behalf. As a result, subjective measures of quality of life have become central to a 'best interests' assessment.[53] This aligns with a proposal for a law on physician-assisted suicide (discussed in Chapter Seven) that is based on a patient's subjective assessment of their quality of life. This is fundamental to an individual being able to express what they find to be a poor and an unacceptable quality of life.

4.3.2 *Mentally disabled adults*

In the 1996 case of *Re R*,[54] the President of the Family Division, Sir Stephen Brown, held that the overriding principle for 'best interests' is the same for mentally disabled adults as for children. The patient was a physically and mentally disabled 23-year-old adult with severe epilepsy and profound learning difficulties. The patient was described as being in a 'low awareness state', with the perception and cognitive faculties of a newborn infant. The Court held that it was not in the patient's best interests to subject him to cardiopulmonary resuscitation ('CPR') in the event of a cardiac arrest. The Court was influenced by Taylor LJ's judgment in *Re J* discussed above.[55] It is submitted that, as with *Re J,* the Court in *Re R* would not have been able to accurately assess whether the patient would have considered his life to be intolerable. With the perception and cognitive faculties of an infant, the patient would not have developed any desires or preferences from which the courts would have been able to assess the patient's 'best interests'. Thus, the Court would have made a paternalistic judgement of the patient's quality of life, when allowing the withholding of treatment. In making this judgement, the Court would have relied on the medical assessments by physicians of the patient's best interests.

The case of *Re R* further demonstrates that the English courts have been trying to include the subjective views of incompetent patients in the 'best interests' assessment. The courts have stressed the need to respect and protect 'patient autonomy' in cases involving the withdrawal and withholding of life-sustaining treatment. The common law

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[51] *Wyatt* (CA)(n43)[91].

[52] Dunn (n21) 126.

[53] ibid 126.

[54] *Re R (Adult: Medical Treatment)* [1996] 2 FLR 99.

[55] *Re J (A Minor)* (ch2 n236).

cases discussed in sections 4.3.1 and 4.3.2 provide support for the inclusion of a patient's subjective assessment of quality of life in the proposed law on physician-assisted suicide for England and Wales.

The following section will show that where patients are in a PVS or experiencing similar severe conditions, the English courts have considered the burdens, benefits and futility of life-sustaining treatment when assessing a patient's 'best interests', and thus in determining their quality of life.

4.3.3 *Permanent vegetative state (PVS) or similar severe conditions*

In *Airedale v Bland*, as discussed in Chapter Two, Bland had been in a PVS for four years after his lungs were crushed in the 1989 Hillsborough football stadium disaster.[56] In 1993, the House of Lords declared that since ANH was of no benefit to Bland, the doctors did not have a duty to continue providing such life-sustaining treatment. As reflected in Lord Goff's judgment:

> If the justification for treating a patient who lacks capacity to consent lies in the fact that the treatment provided is in his best interests, it must follow that the treatment may…be discontinued where it is no longer in his best interests…for my part I cannot see that medical treatment is appropriate or requisite simply to prolong a patient's life, when such treatment has no therapeutic purpose of any kind, as where it is futile because the patient is unconscious and there is no prospect of any improvement in his condition…in the end…it is the futility of the treatment which justifies its termination.[57]

It is argued that the House of Lords had effectively made a judgement of Bland's quality of life, to determine whether ANH should be withdrawn in his best interests. It is submitted that the 'futility of treatment' as referred to by Lord Goff is in effect a quality of life judgement as to whether it is worthwhile to keep the patient alive. The ANH could only truly be considered 'futile' if there was no purpose in maintaining such treatment, whereas the ANH was indeed fulfilling its objective of keeping Bland alive.

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[56] Bland's case (ch1 n12).

[57] ibid 869.

Thus, as Keown forcefully argues, Lord Goff's 'futility of treatment' judgment in fact rested upon the futility of Bland's life.[58]

Lord Keith in Bland's case held that:

> A medical practitioner is under no duty to continue to treat such a patient where a large body of informed and responsible medical opinion is to the effect that no benefit at all would be conferred by continuance. Existence in a vegetative state with no prospect of recovery is by that opinion regarded as not being a benefit.[59]

This reliance on 'a large body of informed and responsible medical opinion', to determine the 'best interests' of Bland, suggests that the English courts are leaving such end-of-life medical decisions to the medical profession. In effect, the House of Lords had relied on the doctors' paternalistic judgement of the patient's quality of life.[60] The subjective views of Bland were nevertheless noted in the *obiter dicta* of Hoffman LJ:

> [t]he patient's best interests would normally also include having respect paid to what seems most likely to have been his own views on the subject. To this extent…'substituted judgement' may be subsumed within the English concept of best interests.[61]

Although the House of Lords in Bland's case concluded that Bland's best interests no longer required continued treatment, Lord Mustill held that, 'This is not at all to say that I would reach the same conclusion in less extreme cases, where the glimmerings of awareness may give the patient an interest which cannot be regarded as null.'[62] Similarly, Lord Browne-Wilkinson in Bland's case emphasised that the patient was an extreme case where it could be overwhelmingly proved that the patient was and would remain insensate, and expressed no view on cases where the chances of improvement were slight or the patient had 'very slight sensate awareness'.[63] Despite these pronouncements that a less extreme case might be considered differently, English courts have gone beyond Bland's case by withholding ANH where there have been such

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[58] Keown (ch3 n47).

[59] Bland's case (ch1 n12) 858-59. See *Bolam* test (n18) for responsible medical opinion.

[60] I Kennedy & A Grubb, 'Withdrawal of Artificial Hydration and Nutrition: Incompetent Adult' (1993)1 Med.L.Rev 359,363.

[61] Bland's case (ch1 n12) 833. See also section 2.3.3 under *Best interests* (ch2 nn302-305).

[62] ibid 899.

[63] ibid 885.

'glimmerings of awareness' and very slight sensate awareness. As Meyers and Mason observe, the post-*Bland* case law on the withdrawal and withholding of ANH from incompetent patients reflects a relaxation of the criteria for a PVS.[64] The cases have been extended to include less well defined medical conditions than the PVS which existed in Bland's case. This extension constitutes a 'slippery slope' in relation to legally permitted end-of-life medical decisions in England and Wales. Such 'slippery slopes' and the argument that they need to be avoided will be dealt with in Chapter Six.

In the 1994 case of *Frenchay NHS Healthcare Trust v S* (*Frenchay* case),[65] less than a year after Bland's case, the court allowed ANH to be withheld from a patient in a state of deep unconsciousness, who demonstrated restlessness and distress that was inconsistent with a PVS. In April 1996, the RCP issued a set of guidelines for the diagnosis of a PVS.[66] English courts have, however, authorised the withdrawal of ANH from patients who did not satisfy these guidelines. In these cases, the patients' conditions were judged to be functionally indistinguishable from a PVS.[67] The President of the Family Division, Sir Stephen Brown, in the 1997 case of *Re H* held that not all patients in a PVS present the same diagnostic indicators, and that some response to stimulation and visual tracking may be compatible with a diagnosis of PVS.[68] In *Re D*, also heard by Sir Stephen Brown in 1997, the patient did not wholly fulfil the RCP's criteria for a PVS as she appeared able to track movement with her eyes and to demonstrate a 'menace' response.[69] Nevertheless, Sir Stephen held that 'for all practical purposes' she was in a PVS, and that 'there is no evidence of any meaningful life whatsoever'.[70] These cases demonstrate that once a patient has lost the capacity for conscious thought, English courts may uphold the withholding or withdrawal of ANH as being in their 'best interests'. As with Bland's case, it is submitted that in the cases of *Frenchay*, *Re H*, and *Re D* the courts made a paternalistic judgement of the patients' quality of life, in determining their 'best interests'. These cases also reaffirm that the doctrine of sanctity of life[71] does not dictate that a patient's best interests require the

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[64] D Meyers and J Mason, 'Physician-Assisted Suicide: A Second View from Mid-Atlantic' (1999)28 Anglo-Am.L.R. 265,274.

[65] *Frenchay NHS Healthcare Trust v S* [1994] 2 All ER 403 ('*Frenchay* case').

[66] Royal College of Physicians Working Group, 'The Permanent Vegetative State' (1996)30(2) Journal of the Royal College of Physicians London 119,119.

[67] *Re H (Adult: Incompetent Patient)* [1998] 2 FLR 36.

[68] ibid 39.

[69] *Re D (Medical Treatment)* [1998] 1 FLR 411,418.

[70] ibid 420.

[71] See section 3.3.1.

prolongation of life. This was emphasised by Sir Stephen Brown in his judgment in *Re H*: '[T]he sanctity of life is of vital importance. It is not, however, paramount'.[72]

As with Bland's case, the court's decision in the 2001 case of *Re G*[73] to withdraw ANH from a patient who was in a PVS was based on a 'best interests' assessment, which was effectively a quality of life judgement. In *Re G*, the patient suffered profound brain damage following surgery and lost all signs of any awareness. After being kept alive for nine months by ANH, the court was asked to authorise its withdrawal. Dame Elizabeth Butler Sloss P held:

> I am…entirely satisfied that there is no reasonable prospect of Mrs G ever recovering at all. Consequently, one has to go on and consider what is in her interests, the best way to deal with this irreversible condition and the prospect that she might live like this for another four to five years. The family have…been consulted…each has carefully considered the implications of allowing [her] to die in peace and with dignity and not to be kept artificially alive…one element of their decision is that she herself if she knew about it would be shocked and appalled at the idea that she was being kept alive like this, that she expressed a strong view during her life…that if she was to be found in this situation she should not be kept alive regardless. I am satisfied that it is appropriate that I…permit Mrs G to die with dignity and in peace by the withdrawal of the artificial nutrition and hydration.[74]

Thus, the court in *Re G* considered the subjective views of the patient in assessing the patient's best interests, consistent with the *obiter dictum* in Bland's case.[75] Based on *Re G*, it is submitted that terminally ill patients who are competent should similarly be allowed to have a physician-assisted suicide based on their subjective personal judgement of their own quality of life. This proposal will be discussed in detail in Chapter Seven.

In its 1999 guidance, the BMA endorsed the withholding and withdrawal of ANH not only from patients who are in a PVS, but also from patients with other serious conditions, such as those with severe dementia or those who have suffered a serious

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[72] *Re H (Adult: Incompetent Patient)* (n67) 40.

[73] *Re G (Adult Incompetent: Withdrawal of Treatment)* (2001) 65 BMLR 6.

[74] ibid 8, 9.

[75] Bland's case (ch1 n12) 833.

stroke.[76] This guidance impacts a broader range of patients who have lost awareness, or whose lives are of poor quality. Additionally, in 2002, the GMC issued guidelines which provided that ‘Where death is imminent and ANH is already in use, it may be appropriate to withdraw such treatment if it is considered that the burdens outweigh the possible benefits to the patient’.[77] The guidelines also stated that:

> Where adult patients lack capacity to decide for themselves, an assessment of the benefits, burdens and risks, and the acceptability of proposed treatment must be made on their behalf by the doctor, taking account of their wishes, where they are known. Where a patient’s wishes are not known it is the doctor’s responsibility to decide what is in the patient’s best interests.[78]

It is submitted that by taking account of the known wishes of the patient, the GMC has incorporated a ‘substituted judgement’ in its guidelines. In this regard, the autonomy of the patient is promoted. Nevertheless, the GMC also places emphasis on medical paternalism in cases where a patient’s wishes are not known, by placing the responsibility on the doctor to decide what is in a patient’s ‘best interests’.

It is contended that the ‘best interests’ assessment pursuant to the GMC guidelines is in effect a quality of life judgement by doctors. The guidelines require a physician to presuppose the quality of life that a patient may live with, by assessing the ‘benefits, burdens, and risks’ which may be associated with treatment.[79] As Brock convincingly asserts, what the doctors are actually asking is:

> Is the patient’s quality of life so poor that the use of life-sustaining treatment is unduly burdensome, such that the burdens to the patient of the treatment and/or the life that it sustains are sufficiently great and the benefits to the

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[76] BMA, *Withholding and Withdrawing Life-prolonging Treatment: Guidance for Decision-Making* (BMJ Books 1999)[21.4]. The BMA subsequently published further editions of its guidance, first in 2001(2nd edn) and then in 2007(3rd edn). These recent guidelines merely endorse the withholding and withdrawal of ANH, from patients suffering other conditions not amounting to PVS.

[77] GMC, *Witholding and Withdrawing Life-prolonging Treatments* (ch2 n278) para 81. This guidance is now superseded by a corresponding provision: GMC, *Treatment and care towards the end of life* (ch2 n278) para123.

[78] GMC, *Witholding and Withdrawing Life-prolonging Treatments* (ch2 n278) para15, now superseded by GMC, *Treatment and care towards the end of life* (ch2 n278) para123.

[79] Beauchamp & Childress (ch2 n253) 102.

> patient of the life that is sustained sufficiently limited, to make continued life on balance no longer a benefit or good to the patient?[80]

A quality of life judgement by doctors is also reflected in the BMA's August 2009 note on end-of-decisions, where it states that life-sustaining treatment can be withheld or withdrawn by doctors when such treatment is unable to benefit an incompetent patient and is accordingly not in their best interests.[81]

The 2005 case of *W Healthcare NHS Trust v KH and Others* (KH's case)[82] demonstrates that where a patient's wishes are unclear, the courts will have to decide whether to withdraw ANH based on what the courts regard to be in the 'best interests' of the patient. In KH's case, the patient suffered from multiple sclerosis and required ANH. She was barely conscious or sentient. When her feeding tube became displaced, the question arose whether it should be replaced. The patient had previously expressly refused medical treatment that did not enable her to continue with a reasonable quality of life, including life support machines. However, the patient had not specifically addressed the issue of ANH. The patient's family had objected to the feeding tube being reinserted, believing that the patient would have refused it. The English courts had to decide whether it was in the patient's best interests that ANH be continued. The Court accepted that the patient had refused to be kept alive on 'life support machines'. However, as there had been no specific refusal of ANH, the Court held that withholding the feeding tube would not be in the patient's best interests. Brooke LJ held that:

> there was not an advance directive which was sufficiently clear to amount to a direction that she preferred to be deprived of food and drink for a period of time which would lead to her death in all circumstances. There is no evidence that she was aware of the nature of this choice, or the unpleasantness or otherwise of death by starvation…The Court cannot in effect sanction the death by starvation of a patient who is not in a PVS state other than with their clear and informed consent or where their condition is so intolerable as to be beyond doubt. This patient is sufficiently conscious and sentient to appreciate and experience the effects of death by starvation over weeks…I cannot say that life-prolonging treatment…would provide no

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[80] DW Brock, *Quality of Life Measures in Health Care and Medical Ethics* (Brown University 1989).

[81] BMA, *End-of-Life Decisions* (ch3 n73).

[82] *W Healthcare NHS Trust v KH* [2004] EWCA 1324 (KH's case).

> benefit…death by this route would in my judgment be even less dignified than the death which she will more probably face at some time in the more distant future.[83]

The 2005 case of *Burke*,[84] discussed in Chapter Two, demonstrates further that the 'best interests' assessment for an incompetent patient is in effect a paternalistic quality of life judgement by doctors. In Burke, the patient suffered from spino-cerebella ataxia, a terminal wasting illness. He was afraid that ANH would be withheld from him at some time in the future, and that he would be aware of the pain and extreme distress that will result from dehydration and malnutrition. The patient requested the right to be given ANH until such time when he died of natural causes. The Court of Appeal held that life-sustaining treatment which places an intolerable burden on an incompetent patient may be withdrawn, if it is clinically determined to be futile and unlikely to be in the patient's best interests. The Court stated that the concept of 'best interests' should be confined to an 'objective test', even though this may conflict with a patient's subjective wishes.

In conclusion, the cases in this section demonstrate that the English courts have been allowing the withdrawal or withholding of ANH from incompetent patients based on a 'best interests' assessment that involves a quality of life judgement by physicians and the courts. To ensure legal and moral consistency, it follows from this, that any proposed law on physician-assisted suicide should also be based on a subjective assessment of quality of life by a terminally ill patient. Today, end-of-life decisions concerning the withdrawal or withholding of life-sustaining treatment from incompetent adult patients are governed by the MCA 2005.

4.3.4 *The Mental Capacity Act 2005 (MCA 2005)*

As discussed in Chapter Two,[85] since 2007, decisions made on behalf of adult patients lacking capacity have to be made based on an assessment of their 'best interests' under the MCA 2005.[86] The MCA 2005 provides that in cases where life-sustaining treatment is futile or overly burdensome to a patient, or where there is no prospect of recovery, an assessment of the patient's 'best interests' may result in the withdrawal or withholding

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[83] ibid [21],[22].

[84] *Burke* (ch2 n277).

[85] See section 2.3.3 under *Best interests*.

[86] MCA sub-s 1(5).

of such treatment.[87] In this regard, the MCA 2005 has endorsed the decisions in the common law cases of *Bland*[88] and *Burke*,[89] and the BMA[90] and GMC[91] guidelines on the withholding and withdrawal of life-sustaining treatment from incompetent patients. In assessing best interests, a decision-maker (e.g. doctors, courts or 'donees'[92]) needs to consider any statements that an incompetent patient has previously made about their wishes and feelings[93] about life-sustaining treatment.[94] The patient's views,[95] beliefs and values[96] will also have to be taken into account. The views of anyone named by the patient as someone to be consulted, or anyone engaged in caring for the patient, or interested in the patient's welfare[97] will also have to be considered.

It is submitted that the 'best interests' assessment under the MCA 2005 is not limited to an objective assessment about what is clinically most appropriate for the patient, but rather it encompasses much more subjective considerations about what treatment would best complement the patient's values and preferences.[98] As established in Chapter Two, an assessment of 'best interests' which recognises a patient's previous wishes and feelings, contains a strong element of the 'substituted judgment' standard. This allows for a 'best interests' assessment that upholds patient autonomy[99] where appropriate, and is thus based on a patient's subjective evaluation of quality of life.[100]

As noted in Chapter Two, others (even loved ones) may not always know the past preferences, beliefs and values of a patient.[101] A patient's wishes and feelings may also

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[87] ibid, Code of Practice para 5.31.

[88] Bland's case (ch1 n12).

[89] *Burke* (ch2 n277).

[90] BMA, *Withholding and Withdrawing Life-prolonging Treatment* (n76)[21.4]. See also BMA, *End-of-life decisions* (ch3 n73).

[91] GMC, *Witholding and Withdrawing Life-prolonging Treatments* (ch2 n278) para15, now superseded by GMC, *Treatment and care towards the end of life* (ch2 n278) para123.

[92] A lasting power of attorney ('LPA') under the MCA enables a competent patient to appoint a personal welfare donee to make decisions, including medical decisions, on their behalf when they lack capacity: MCA s 9. An LPA does not authorise a donee to refuse life-sustaining treatment, unless there is an express provision to that effect: ibid sub-s 11(7).

[93] ibid sub-s 4(6).

[94] ibid, Code of Practice para5.32.

[95] ibid, Code of Practice para5.41.

[96] ibid, Code of Practice para5.46.

[97] ibid sub-s 4(7).

[98] E Jackson, 'The minimally conscious state and treatment withdrawal: W v M' (Epub 5 November 2012) J Medical Ethics.

[99] See section 3.3.4.

[100] Donnelly (ch2 n290) 15.

[101] ibid 24, 26.

not remain the same following their incapacity.[102] As such, family members and even close friends may not have an accurate idea of a patient's values or preferences.[103] This is supported by Sulmasy et al's American study, which showed that many family members who act as 'surrogates' cannot accurately predict what patients would have chosen in particular situations.[104] In the 2011 case of *Re M,* the court considered an application to withdraw ANH from a patient diagnosed as being in a 'minimally conscious state', as distinct form a PVS. Baker J held that when considering the past wishes of M as required by section 4(6) of the MCA 2005, he could not attach 'any significant weight' to the past statements of M because (i) M's past statements didn't specifically address M's current condition of being in a 'minimally conscious state', and (ii) 'there is no way of knowing [M's] current views, having lived in that state for over eight years.'[105]

English researchers Addington-Hall and Kalra, found that surrogates may also be influenced by their personal feelings and by their experiences of caring for the patient.[106] With particular reference to older people, Wicclair observed that, many elderly people do not discuss their preferences and when elderly people do talk to their families about future care, comments may be vague, off-hand and ambiguous. He noted further that family members may also disagree regarding preferences, and conflicts of interest between family members may influence interpretations of a patient's views.[107]

The 2013 decision of *Aintree University Hospitals NHS Foundation Trust v James* (the *Aintree NHS Trust* case)[108] is the first case to be decided by the Supreme Court on the 'best interests' assessment under the MCA 2005. The appeal was concerned with how doctors and courts should decide whether it is in the 'best interests' of an incompetent patient to be given life-sustaining treatment. In clarifying the best interests assessment under the MCA 2005, Lady Hale held:

> in considering the best interests of a…patient…decision-makers must look

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[102] ibid 24, 26.

[103] EJ Emanuel, LL Emanuel, 'Proxy decision-making for incompetent patients: an ethical and empirical analysis' (1992)267 JAMA 2067.

[104] D Sulmasy et al, 'The Accuracy of Substituted Judgments in Patients with Terminal Diagnosis' (1998)128 Ann Intern Med 621.

[105] *Re M* (ch2 n311) at [230].

[106] J Addington-Hall, L Kalra, Measuring quality of life, Who should measure quality of life? (2001)322 BMJ 1417.

[107] M Wicclair, *Ethics and the Elderly* (New York: OUP, 1993),55–56.

[108] *Aintree NHS Trust* case (ch2 n306).

> at [the patient's] welfare in the widest sense, not just medical but social and psychological; they must consider the nature of the medical treatment in question, what it involves and its prospects of success; they must consider what the outcome of that treatment for the patient is likely to be; they must try and put themselves in the place of the…patient and ask what [the patient's] attitude is or would be likely to be; and they must consult others who are looking after [the patient] or interested in [the patient's] welfare.[109]

Lady Hale's judgment further states that:

> The purpose of the best interests test is to consider matters from the patient's point of view. That is not to say that his wishes must prevail, any more than those of a fully capable patient must prevail. We cannot always have what we want. Nor will it always be possible to ascertain what an incapable patient's wishes are. Even if it is possible to determine what his views were in the past, they might well have changed in the light of the stresses and strains of his current predicament…insofar as it is possible to ascertain the patient's wishes and feelings, his beliefs and values or the things which were important to him, it is those which should be taken into account because they are a component in making the choice which is right for him as an individual human being.[110]

It is submitted that the *Aintree NHS Trust case* has confirmed that the 'best interests' assessment under the MCA 2005 is not an 'objective test', but one that requires a patient's subjective interests to be considered. By emphasising 'welfare in the widest sense', Lady Hale's judgment is essentially also supporting a subjective patient evaluation of quality of life.

As noted in Chapter Two,[111] two recent cases under the MCA 2005 where a patient's expressed views have not prevailed when assessing their 'best interests' are L's case[112] and E's case[113]. In L's case, the patient's assessment was overridden by the common law principle that 'doctors cannot be required to provide treatment which is contrary to their

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[109] ibid [39].

[110] ibid [45].

[111] See Section 2.3.3 under *Best interests*.

[112] L's case (ch2 n312).

[113] E's case (ch2 n321).

professional judgement',[114] and was also strongly outweighed by the quality of life assessments of his physicians. In E's case, the patient's assessment was considered as one of several factors under the MCA 2005. These factors were determined by Jackson J to be 'almost exactly in equilibrium'.[115] However, after careful consideration, Jackson J overruled the patient's wish to not receive any further treatment, and determined that 'the presumption in favour of the preservation of life is not displaced'.[116]

In conclusion, the Supreme Court decision in the *Aintree NHS Trust case* clarifies that the assessment of best interests under the MCA 2005 promotes 'patient autonomy' where possible (noting exceptions such as E's case and L's case above), and thus encourages a subjective evaluation of quality of life. This subjective approach is consistent with the law reforms proposed in Chapter Seven of this thesis. Under that proposal, a competent terminally ill patient would be permitted to make a request for physician-assisted suicide based on their subjective assessment of their quality of life.

The following section will examine the concept of quality of life in respect of treatment decisions concerning terminally ill patients. It will consider subjective and objective evaluations of quality of life, and the scope of issues covered by the concept of quality of life.

4.4 What is 'quality of life'?

This section will firstly consider definitions of 'quality of life', by addressing the dynamics of the two types of quality of life evaluation – patient evaluation and professional evaluation.

4.4.1 *Definition*

'Quality of life' is a broad concept that covers both the actual and perceived level of fulfilment across physical, psychological and social aspects of an individual's life.[117] Thus, quality of life is a combination of a subjective and objective evaluation of one's quality of life.

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[114] L's case (ch2 n312) at [78].

[115] E's case (ch2 n321) at [140].

[116] ibid at [140].

[117] D Chisholm et al, 'QALYs and Mental Health Care' (1997)32 Social Psychiatry Psychiatric Epidemiology 68,69.

– *A subjective patient evaluation*

Although most definitions of ‘quality of life’ are multidimensional, and refer to a patient’s satisfaction levels with multiple areas of their life, there is no consensus as to which areas of life should be included.[118] Barofsky argues that this lack of consensus is attributable to the subjective nature of quality of life.[119] This is also noted by Rummans et al’s 2007 research on quality of life at the end of life. Rummans et al found that a terminally ill patient’s quality of life is based on their subjective experience of living with the interpersonal, psychological, and existential or spiritual challenges that accompany the process of physical and functional decline, and with the knowledge of their impending demise. Their research showed that a patient’s experiences contribute to their attitude toward their health condition and their belief about having the capacity to cope. These will be unique to each individual.[120] Similarly, O’Boyle argues that only individuals can judge their own quality of life, and that they do so in the context of their own expectations, experiences, hopes and ambitions, fears, philosophies, perceptions and beliefs.[121] This is clearly demonstrated in the four cases of *Re B*,[122] Daniel James,[123] *Pretty*,[124] and *Nicklinson*.[125]

– *An objective professional evaluation*

Healthcare professionals often make quality of life judgements when making treatment decisions concerning the terminally ill.[126] These decisions address treatment regimens and therapeutic interventions,[127] including decisions on the withdrawal or withholding of

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[118] LL Steele et al, ‘The quality of life of hospice patients: Patient and provider perceptions’ (2005)22(2) Am J Hospice& Palliative Med 95,95.

[119] I Barofsky. ‘Function states: Quality of life’ in JCB Holland (ed), *Proceedings of Conference on Research Methodology in Psychosocial Oncology* (1984)53(supp) Cancer 2299.

[120] TA Rummans et al, ‘Maintaining Quality of Life at the End of Life’ (2000)75 Mayo Clinic Proceedings 1305.

[121] CA O’Boyle, ‘Assessment of quality of life in surgery’ (1992)79 Br J Surgery 395.

[122] *Re B (Adult: Refusal of Treatment)* (ch1 n42).

[123] ‘Decision on Prosecution — The Death by Suicide of Daniel James’ (ch1 n25).

[124] *Pretty* (HL)(ch1 n41) [1].

[125] *Nicklinson* (CA)(ch1 n10) [140]. Two more recent cases involving a subjective patient evaluation of quality of life are the cases of Paul Lamb and Martin. Like Nicklinson who died in 2012, Martin suffers from locked-in syndrome. Lamb, on the other hand, is paralysed. See R Cooper, ‘“I was hoping for a dignified end. This judgement does not give me that”: Disappointment of paralysed man as he loses his right-to-die plea’ *Daily Mail* (London, 31 July 2013).

[126] AR Manara et al, ‘Reasons for withdrawing treatment in patients receiving intensive care’ (1998)53 Anaesthesia 523.

[127] TM Gill et al, ‘A Critical Appraisal of the Quality of Quality-of-Life Measurements’ (1994)272(8) JAMA 619.

life-sustaining treatment from incompetent patients (discussed above).[128] Some of these quality of life judgements by healthcare professionals form part of the procedures covered by the *Liverpool Care Pathway for the Dying Patient* (‘*LCP*’).[129] The *LCP*’s procedures have enabled doctors to select palliative care,[130] and other treatment options for terminally ill patients, when it is judged to be no longer beneficial to keep the patient alive. These options include the withholding and withdrawal of life-sustaining treatment from incompetent patients and medical decisions with a ‘double effect’.[131] Quality of life assessments made by healthcare professionals may be contrary to those of their patients.[132] This was illustrated in the case of *Re B*, in which the patient had found her quality of life unacceptable and refused a life-sustaining ventilator, despite a contrary view being held by her physicians.[133] This was also illustrated in L’s case,[134] a case under the MCA 2005. As noted in Chapter Two,[135] the court in L’s case accepted that an incompetent patient, L, would find his quality of life acceptable after a course of CPR (if ever required), despite a unanimous view by physicians that the application of CPR would do L more harm than good.

Particularly in the case of a subjective patient evaluation, ‘quality of life’ is a dynamic construct that alters in response to illness over time.[136] As Sprangers and Schwartz assert, changes in one’s assessment of quality of life that occur during a terminal illness result partly from patients adapting to the new situation in which they find themselves.[137] Addington-Hall and Kalra observe that patients assess their quality of life differently than they would have if they had not adapted to their illnesses. They refer to this phenomenon of internal adaptation as a ‘response shift’.[138] Patients may also adapt to their illnesses as the result of effective palliative care treatment that successfully controls symptoms and manages pain. For these reasons, it is submitted that it is

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[128] *Burke* (ch2 n277)[29]-[30].

[129] See ch3 nn232-235.

[130] See section 3.4.3.

[131] See *LCP Model Pathway UK Core Documentation* (ch3 n234). See sections 2.3.1 and 3.3.6 on ‘doctrine of double effect’.

[132] S Hallan et al, ‘Quality of life after cerebrovascular stroke: a systematic study of patients’ preferences for different functional outcomes’ (1999)246 J Internal Medicine 309.

[133] *Re B (Adult: Refusal of Treatment)* (ch1 n42).

[134] L’s case (ch2 n312).

[135] See Section 2.3.3 under *Best interests*.

[136] AJ Carr, IJ Higginson, ‘Measuring quality of life - Are quality of life measures patient centred?’ (2001)322 BMJ 1357.

[137] MA Sprangers, CE Schwartz, ‘Integrating response shift into health-related quality of life research: a theoretical model’ (1999)48 Soc Sci Med 1507.

[138] Addington-Hall, Kalra (n106). See section 3.4.3. See also text to n39.

essential to define quality of life in terms of subjective evaluations by patients, rather than in terms of objective evaluations by healthcare professionals.[139]

The scope of quality of life will be considered below. Quality of life has tended to be described from two viewpoints, one in terms of health, and the second in a wider global sense.[140]

4.4.2 *Scope*

– *Health-related quality of life*

As discussed above, quality of life for a patient relates to a subjective sense of well-being.[141] Thus, a 'health-related quality of life' measure needs to capture a patient's own perspective of their illness and treatment.[142] Revicki et al define 'health-related quality of life' as the subjective assessment of the impact of either a medical condition or of specific medical interventions on a person's physical, psychological, social and somatic domains of functioning and well-being.[143] The Canadian commentators, Michael and Tannock, divide 'health-related quality of life' factors into three categories: those related to general health (including physical factors like mobility and fatigue; social factors like relationships, and emotional support; and psychological factors like anxiety, fear, depression), those directly related to the disease (including pain, and nausea), and those related to treatment (including nausea, hair loss, drowsiness, and confusion).[144] Their definition of health-related quality of life goes beyond the narrow scope of a purely medical and physical diagnosis.

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[139] AL Stewart et al, 'The Concept of Quality of Life of Dying Persons in the Context of Health Care' (1999)17(2) J Pain Symptom Manage 93.

[140] WR Tang et al, 'Quality of Life in Hospice Patients with Terminal Illness' (2004)26(1) Western J Nursing Research 113.

[141] WM Gill, 'Subjective well-being: properties of an instrument for measuring this in the chronically ill' (1984)18(8) Soc Sci Med 683.

[142] IJ Higginson, AJ Carr, 'Measuring quality of life - Using quality of life measures in the clinical setting' (2001)322 BMJ 1297.

[143] DA Revicki et al, 'Recommendations on health-related quality of life research to support labelling and promotional claims in United States' (2000)9 Quality Life Research 887.

[144] M Michael, IF Tannock, 'Measuring health-related quality of life in clinical trials that evaluate the role of chemotherapy in cancer treatment' (1998)158 Can Med Assoc J 1727.

– *Global quality of life*

Those defining quality of life according to a wider global sense, tend to add additional dimensions, such as an existential dimension.[145] In their study of how best to measure the quality of life of the terminally ill, Byock and Merriman found that existential well-being embodies an individual's ability to find meaning and purpose in life and to rise above physical discomfort, accept death, and feel at peace.[146] Similarly Stewart et al observed that the terminally ill become increasingly concerned about their peace of mind, comfort, spirituality, and 'transcendence', which Stewart et al defined as making peace with life or God before death.[147] Cohen and Mount further found that as a person's physical condition declines at the end of life, existential, spiritual, and social issues gain in importance for them.[148]

Having considered a 'health-related quality of life' and a 'global quality of life', it is the former that will be adopted for the purposes of law reform in this thesis. It will be proposed in Chapter Seven that a law that permits physician-assisted suicide, based on quality of life, should restrict the concept of quality of life to those aspects of life which are affected by a person's medical condition and its treatment.[149] Physician-assisted suicide should only be available to terminally ill patients experiencing a poor and unacceptable quality of life due to the unbearable pain and suffering that is caused by their terminal illness. As Sheldon asserts, a patient's unacceptable quality of life must be due to a medically classified cause, either physical (somatic) or psychiatric.[150]

In terms of measuring a wider global sense of quality of life, a physician would not be able to assess dimensions involving hopeless despair, loneliness, or existential suffering caused by an inability to adapt to one's new situation.[151] Griffiths et al explain that:

> a doctor who assists in suicide in a case in which the patient's suffering is

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[145] M Grant et al, 'Assessment of quality of life with a single instruments' (1990)6(4) Seminars in Oncology Nursing 260.

[146] IR Byock, MP Merriman, 'Measuring quality of life for patients with terminal illness: the Missoula-Vitas Quality of Life Index' (1998)12 Palliative Medicine 231.

[147] Stewart (n139).

[148] SR Cohen, BM Mount, 'Quality of life in terminal illness: defining and measuring subjective well-being in the dying' (1992)8 J Palliat Care 40.

[149] RA Kane, 'Definition, Measurement, and Correlates of Quality of Life in Nursing Homes: Toward a Reasonable Practice, Research, and Policy Agenda' (2003)43(II) Gerontologist 28.

[150] T Sheldon, 'Being "Tired of life" is not grounds for euthanasia' (2003)326 BMJ 71.

[151] U de Vries, 'A Dutch Perspective: The Limits of Lawful Euthanasia' (2004)13 Annals Health Law 365,387,390.

> not predominantly due to a 'medically classified disease or disorder'…acts outside the scope of his professional competence.[152]

Griffiths et al were commenting on the 2003 Dutch case of *Sutorius* (discussed in Chapter Five), in which a physician had assisted the suicide of an elderly patient who merely experienced physical decline, struggled with his 'pointless and empty existence', and felt socially isolated.[153]

The following section will consider the challenges faced by physicians when measuring the quality of life of terminally ill patients for the purposes of treatment decisions.

4.5 Measuring quality of life

Testa et al observe that within medical practice, the lack of an agreed definition of 'quality of life' has resulted in a wide variety of techniques to measure quality of life.[154] Measurement techniques may involve the patient completing a questionnaire (a patient self-report), or being asked questions by an observer who records the patient's response (an indirect patient report).[155] Bergner states that health-related quality of life, as discussed above, is generally measured in two dimensions – objective assessments of functioning or health status, and more subjective perceptions of health.[156] As quality of life should be based on a subjective patient evaluation (discussed above), it is argued that measurement instruments should assess quality of life from the patient's own perspective.[157] Patients know which quality of life issues are of most concern to them.[158] Treatment decisions can then be based on their priorities and preferences.[159]

There have been several instruments designed by the medical profession to specifically measure health-related quality of life at the end of life. These include the Amyotrophic Lateral Sclerosis Assessment Questionnaire (ALSAQ-40),[160] the McGill Quality of Life

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[152] J Griffiths et al, *Euthanasia and Law in Europe* (Hart Publishing 2008) 37.

[153] T Sheldon, 'Dutch GP Cleared after Helping to End Man's "Hopeless Existence"' (2000)321 BMJ 1174.

[154] MA Testa et al, 'Assessment of Quality-of-Life Outcomes' (1996)334 The N Engl J Med 835.

[155] DF Cella, 'Quality of life: Concepts and definition' (1994)9 J Pain Symptom Manage 186.

[156] M Bergner, 'Quality of life, health status, and clinical research' (1989)27 Medical Care S148.

[157] Cella (n155).

[158] CA O'Boyle, D Waldron, 'Quality of life issues in palliative medicine' (1997)244(4) J Neurology S18.

[159] Higginson, Carr (n142).

[160] This is a disease-specific quality of life instrument for motor neurone disease. Diane Pretty suffered from motor neurone disease, see ch2.

(MQOL) questionnaire,[161] the Hospice Quality of Life Index (HQLI),[162] the Missoula-VITAS Quality of Life Index (MVQOLI),[163] the McMaster Quality of Life Scale (MQLS),[164] the adapted European Organization for Research and Treatment of Cancer (EORTC) questionnaires,[165] the Functional Assessment of Chronic Illness Therapy – Palliative Care (FACIT-Pal),[166] and the Schedule for the Evaluation of Individual Quality of Life (SEIQoL)[167]. Each instrument is designed to accommodate the unique experiences of dying patients, and to assess patients who either have a specific diagnosis or who are at a specific stage of illness.[168]

It is well known that there are often methodological challenges with using such quality of life instruments on terminally ill patients, due to their fragile state of health.[169] Patients may be too ill to complete an assessment.[170] There is also a tendency by patients to under-report their psychological and physical complaints.[171] Cognitive impairment (which is prevalent in palliative care[172]) may also affect data quality.[173] In such cases, a healthcare professional or family member of the patient may make an assessment of the patient's quality of life instead.[174] Studies show that such third party assessments can provide useful information on more observable aspects of quality of life,[175] like

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[161] SR Cohen et al, 'The McGill quality of life questionnaire: a measure of quality of life appropriate for people with advanced disease. A preliminary study of validity and acceptability' (1995)9 Palliative Medicine 207.

[162] SC McMillan, M Weitzner, 'Quality of life in cancer patients: use of a revised Hospice Index' (1998)6 Cancer Practice 282.

[163] Byock, Merriman (n146).

[164] Cohen, Mount (n148).

[165] NK Aaronson et al, 'The European Organization for Research and Treatment of Cancer QLQ-C30: a quality-of-life instrument for use in international clinical trials in oncology' (1993)85 J Natl Cancer Ins 365.

[166] J Teno & KE Landrum, *Toolkit of Instruments to Measure End of Life Care: Briefing Book for the Conference on Measuring Care at the End of Life* (Center to Improve Care of the Dying 1996).

[167] HM McGee et al, 'Assessing the quality-of-life of the individual: The SEIQoL with a healthy and a gastroenterology unit population' (1991)21 Psychological Medicine 749.

[168] KE Steinhauser, 'Measuring quality of life at the end of life: Validation of the QUAL-E' (2004)2 Palliative and Supportive Care 3.

[169] SR Cohen et al, 'Changes in quality of life following admission to palliative care units' (2001)15 Palliative Medicine 363.

[170] GN Thompson, 'Methodological Challenges in Measuring Quality Care at the End of Life in the Long-Term Care Environment' (2006)32(4) J Pain Symptom Manage 378.

[171] M Bullinger, 'Quality of life assessment in palliative care' (1992)8 J Palliat Care 34.

[172] See section 3.4.3.

[173] J Robinson, 'Cognitive assessment of palliative care patients' (1999)7 Progressive Palliative Care 291.

[174] O'Boyle, Waldron (n158).

[175] HR Jocham et al, 'Quality of life in palliative care cancer patients: a literature review' (2006)15 J Clinical Nursing 1188.

functional health, overall health and social activity.[176] However, studies also demonstrate that such third party assessments are less accurate for the more subjective aspects of a patient's life.[177] It is concluded that, assessments which rely on a third party assessment of a patient's quality of life should be interpreted cautiously, and should generally be accorded less weight than those that use a patient's own assessment.[178] As convincingly argued by Nekolaichuk et al, third party assessments for patients at the end of life should only be used as a partial substitute for 'quality of life' self-assessments by patients themselves.[179] It is submitted however that for the purposes of law reform in this thesis, third party assessments will not be accepted. Quality of life assessments will be based on the subjective patient evaluation of a competent terminally ill patient who is capable of not only making an autonomous request for physician-assisted suicide, but also of then carrying out the act to end their own life.

4.6 Conclusion

From an analysis of the extent to which 'quality of life' has been considered in end-of-life medical decisions, this chapter concludes that the law on assisted death is unsatisfactory. The chapter finds that 'quality of life' has been an influence on legally permitted end-of-life medical decisions in England and Wales.

The chapter established that the English courts have made 'quality of life' assessments when determining the 'best interests' of critically ill and severely disabled newborn babies, and mentally disabled adults. In deciding whether to allow the withdrawal or withholding of life sustaining treatment — *Re B (A Minor)*, *Re J*, *Wyatt*, and *Re R* all showed that courts have looked at issues like 'intolerability', a patient's 'assumed view', and that they have applied an objective welfare appraisal in assessing a child's best interests. From *Re J*, *Wyatt*, and *Re R*: the chapter found that applying a 'substituted judgement' for a newborn baby or a mentally disabled adult, as a means of respecting their autonomy, is purely speculative. Similarly, the chapter found that in cases involving patients in a PVS (Bland's case, *Re G*), or with similar severe

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[176] AM Epstein et al, 'Using Proxies to Evaluate Quality of Life: Can They Provide Valid Information about Patients' Health Status and Satisfaction with Medical Care?' (1989)27(3) Medical Care S91.

[177] LZ Rubenstein et al, 'Systematic biases in functional status assessment of elderly adults: effects of different data sources' (1984)39 J Gerontology 686.

[178] C Salisbury et al, 'The impact of different models of specialist palliative care on patients' quality of life: a systematic literature review' (1999)13 Palliative Medicine 3.

[179] CL Nekolaichuk et al, 'A comparison of patient and proxy symptom assessment in advanced cancer patients' (1999)13 Palliative Medicine 311.

conditions (*Frenchay* case, *Re H*, and *Re D*), the English courts have effectively made 'quality of life' assessments to determine whether ANH should be withdrawn in the 'best interests' of a patient. In this respect, the law on assisted death in England and Wales is inconsistent. It purports to respect the autonomy of an incompetent patient when removing life-sustaining treatment, whilst ignoring the autonomous wishes of a competent patient who requests an assisted death. The ethical presumption of the sanctity of life is rebuttable when removing life-sustaining treatment, but considered irrebuttable in those cases involving requests for assisted death.

This chapter demonstrated that vulnerable incompetent patients are protected by the MCA 2005, whilst also being empowered to participate in decisions made in their 'best interests' through the consideration given to their previously expressed wishes and preferences. This is in contrast to the requests for assisted death by competent patients — where no legislation has yet been enacted to empower such patients, whilst protecting and empowering the vulnerable as happens under the MCA. To-date, the only protection offered the vulnerable with regard to assisted death has been to impose a blanket prohibition on the practice.

This chapter supports a proposal for law reform that enables a competent terminally ill patient to make a request for physician-assisted suicide based on their own subjective assessment of their quality of life. The chapter established that physicians often make quality of life judgements when making treatment decisions concerning terminally ill patients. However, these quality of life judgements by physicians may be contrary to those of their patients (e.g. *Re B*[180] and *Burke*[181]). The chapter established that 'quality of life' is a dynamic construct that alters over time. 'Quality of life' changes often occur during terminal illness, as patients adapt to their illness. The chapter concluded that it is essential to define 'quality of life' in terms of a subjective evaluation by the patient. Health-related quality of life measures need to capture a patient's subjective assessment of the impact of their medical condition and of medical interventions on their physical and psychological well-being.

The chapter established that 'health-related quality of life' is generally measured in two dimensions – objective assessment of health status and subjective perceptions of health. However, as quality of life should be based on a subjective evaluation, the chapter

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[180] *Re B (Adult: Refusal of Treatment)* (ch1 n42).

[181] *Burke* (ch2 n277).

concluded that any measurement instruments employed, should be ones which assess quality of life from a patient’s perspective. Nevertheless, the chapter acknowledged that there are methodological challenges using quality of life instruments to assess terminally ill patients, as patients may be too ill to complete the assessments.

This chapter informs the proposal made in Chapter Seven for a law that enables a competent patient who is terminally ill to make a request for physician-assisted suicide based on a quality of life judgement that is subjectively assessed by the patient, according to the level of pain and suffering caused by their terminal illness. The ‘quality of life’ requirement proposed would be restricted to aspects of life affected by a person’s terminal illness and its treatment.

The following chapter will review the laws which govern euthanasia and assisted suicide in the Netherlands, Belgium, Switzerland, Germany, the Northern Territory (Australia) and Oregon (US), to identify features of these laws which potentially resolve issues of debate, and which might be adopted in England and Wales. The chapter will also examine whether ‘quality of life’ has been an influence on any of these laws.

Chapter 5: Analysis of the Law of Assisted Death in Other Jurisdictions

5.1 Introduction

Having considered the extent to which English law has allowed ‘quality of life’ to influence decisions on end-of-life in Chapter Four, this chapter will examine the laws which govern euthanasia and assisted suicide in six other jurisdictions — the Netherlands, Belgium, Switzerland, Germany, the Northern Territory (Australia), and Oregon (US). Although the Netherlands, Belgium, Switzerland and Germany have civil law systems, and the Northern Territory and Oregon have common law systems, the chapter will identify common themes in these legal regimes. The laws of these jurisdictions are a source of knowledge which can inform prospective law reform in England and Wales.

Assisted suicide is currently expressly provided for by law in the Netherlands, Switzerland, and Oregon, while there is legislation for euthanasia in Belgium and also in the Netherlands. In the Northern Territory, euthanasia and assisted suicide were temporarily legalised from July 1996 until March 1997. In all jurisdictions except Switzerland and Germany, assisted death[1] has been carried out by physicians. In Germany, assisted suicide may be practised by anyone other than physicians because although it is not expressly permitted by law, there is no law that explicitly forbids it. The chapter will demonstrate that autonomy[2] and self-determination[3] have been the main ethical influences for encouraging a more permissive environment in respect of assisted death in these jurisdictions. Nevertheless, it will also be shown that there is an element of medical paternalism, where non-voluntary euthanasia[4] is practised.

The chapter will identify features of these foreign laws which potentially resolve issues of debate in England and Wales.[5] The chapter will show that two essential safeguards for a law on assisted death are a mandatory mental health evaluation and the option for palliative care. It will be demonstrated that in jurisdictions where non-medically

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[1] ‘Assisted death’, defined in section 1.1.

[2] See section 3.3.4.

[3] See section 3.3.2.

[4] ‘Non-voluntary euthanasia’ (text to ch1 n98).

[5] Sacco (ch1 n160).

qualified people assist in deaths, there is a lack of medical knowledge to address or manage complications during a patient's dying process, and a risk of failure to detect clinical depression or other mental disorders in vulnerable patients[6]. The chapter will examine studies and surveys of these jurisdictions, first, to consider the impact of their laws on assisted death,[7] and, secondly, to assess the efficacy of each jurisdiction's approach to assisted death in the context of their particular cultural and legal background.[8] The chapter will examine whether the laws in each of these jurisdictions have been effective in response to the jurisdiction's initial call for reform, and whether these laws have been abused. Insights gained into the different legal approaches to assisted death in these jurisdictions will inform the law reform agenda for the legalisation of physician-assisted suicide in England and Wales, addressed in Chapter Seven.

The following section examines the development of the law on euthanasia and assisted suicide in the first of the six jurisdictions to be considered — the Netherlands.

5.2 The Netherlands

The Netherlands was the first country in the world to legalise both euthanasia and assisted suicide.[9]

5.2.1 *Background*

The Dutch have followed a tradition of 'legal prohibition and practical tolerance' since the 17th century.[10] They hold a view that any type of behaviour should be tolerated, provided that it does not harm others.[11] This view is similar to Mill's principle of liberty, '[T]he only purpose for which power can be rightfully exercised over any member of a civilized community, against his will, is to prevent harm to others.'[12] Painton notes that a basic premise of the Dutch culture is the belief that the government and the law should

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[6] See section 3.4.6.

[7] Orucu (ch1 n123) 442.

[8] P De Cruz, *Comparative Law in a Changing World* (3rd edn, Routledge and Cavendish 2007).

[9] G Bosshard et al, 'A Role for Doctors in Assisted Dying? An Analysis of Legal Regulations and Medical Professional Positions in Six European Countries' (2008)34 J Medical Ethics 28.

[10] Reeves, 'The Permissive Dutch' *New York Times* (New York,20 October 1985).

[11] P Zisser, 'Euthanasia and the Right to Die: Holland and the United States Face The Dilemma' (1988)9 N.Y.Sch.J.Int'l.& Comp.L 361,363.

[12] Mill (ch3 n101) 9-10.

be used as ‘instruments of altruism’. Thus, regardless of the inherent complications, the Dutch address all problems openly to allow the incorporation of a solution into the law.[13]

The Dutch legal system is based on a civil code, under which public prosecutors, judges, and lawyers work together to arrive at decisions that meet the needs of Dutch society.[14] Dutch public prosecutors may refrain from prosecution if it does not serve the public interest or if an offence can be more effectively dealt with through other measures.[15] This is similar to the powers of the DPP in England and Wales. Where there is sufficient evidence to justify a prosecution for a criminal offence, the DPP has a discretion to consider whether a prosecution is required in the public interest.[16]

Unlike the GMC and BMA in England and Wales, which both maintain that the underlying ethics of medicine is in conflict with the ethics of assisted death,[17] the Royal Dutch Medical Association (‘KNMG’)[18] has always supported physician-assisted death. For those who are not able to physically commit suicide without medical assistance, the KNMG did not think it was practical to endorse only physician-assisted suicide, and deny more active medical help in the form of euthanasia.[19] As observed by Kimsma, suicide assistance provided in the form of oral preparations may not be sufficiently effective for some patients. There will always be patients who cannot drink, who are only semi-conscious, or who prefer that a physician perform euthanasia.[20]

Voluntary euthanasia[21] and assisted suicide were technically illegal in the Netherlands until the enactment of the Termination of Life on Request and Assisted Suicide (Review Procedures) Act 2001 (‘Dutch Act’), which came into force on 1 April 2002.
Article 293 of the Dutch Penal Code (‘DPC’) states that an individual found guilty of killing another at the latter’s request may be sentenced to up to 12 years of imprisonment, and Article 294 prohibits an individual from assisting or inciting another

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[13] F Painton, ‘Tolerance Finally Finds Its Limits’ *Time* (New York,31 August 1987).

[14] H Hendin, ‘The Dutch Experience’ (2002)17 Issues L.&Med. 223,236.

[15] J Fionda, *Public Prosecutors and Discretion: A Comparative Study* (OUP 1995) 98-99.

[16] CCP (ch1 n33).

[17] See section 3.3.3.

[18] *Koninklijke Nederlandse Maatschappij tot bevordering der Geneeskunst* [the Royal Dutch Medical Association].

[19] Board of the KNMG, *Standpunt Inzake Euthanasie* [‘Standpoint on Euthanasia’] (1984) 31Medisch Contact 990 [Walter Lagerwey(tr), ‘KNMG Guidelines for Euthanasia’ (1988)3 Issues L.&Med. 429].

[20] GK Kimsma, ‘Euthanasia Drugs in the Netherlands’ in DC Thomasma et al(eds), *Asking to Die: Inside the Dutch Debate about Euthanasia* (Kluwer Academic Publishers 1998) 135,142–143.

[21] ‘Voluntary euthanasia’ (ch1 n7).

person to commit suicide, with a possible sentence of three years imprisonment.[22] Despite this, for almost two decades, Dutch public prosecutors had declined to prosecute physicians who assisted deaths, provided they complied with the 'due care' criteria laid down by the Dutch Supreme Court in the 1984 case of *Schoonheim*.[23] The 'due care' criteria allowed the *noodtoestand* defence (defence of necessity) to provide the legal justification for assisted deaths. The defence is recognised under Article 40 of the DPC. It provides that an individual faced with two conflicting duties, may violate one to avoid violating another of greater moral significance.[24] It is submitted that in this respect, Dutch law is in sharp contrast to English law. As was reaffirmed recently by the Court of Appeal in *Nicklinson*, English law does not recognise a defence of necessity in cases of assisted death.[25]

As appropriately noted by DiCamillo, the underlying ethical influence which allowed voluntary euthanasia and assisted suicide by Dutch physicians to take place in the Netherlands before the Dutch Act was one's right to self-determination.[26] This is illustrated in the cases that will be discussed below.

Euthanasia was first considered by the District Court at Leeuwarden in the 1973 *Postma* case, in which a physician administered a fatal dose of morphine to her 78-year old terminally ill mother, who had repeatedly requested for death.[27] As the physician had administered a single fatal injection, she was found guilty of euthanasia under Article 293 of the DPC. However, she was only given a one week conditional prison sentence that was subject to a one year probationary period.[28] The Court further stated that the physician would have escaped conviction had she pursued a course of alleviation of symptoms, by administering pain relieving medication in quantities that may also have

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[22] *Wetboek van Strafrecht* [Penal Code] arts293-294 [L Rayar et al(trs), *The Dutch Penal Code* (American Series of Foreign Penal Codes vol 30, Rothman 1997)].

[23] Mendelson & Jost (ch1 n140) 130. See Schoonheim case, *Hoge Raad (Strafkamer)* [Supreme Court (Criminal Division)] 27 November 1984 reported in *Nederlandse Jurisprudentie* 1985 nr106:451. See also text to nn32-36.

[24] J Keown, *Euthanasia, Ethics and Public Policy: An Argument against Legalisation* (CUP 2002) 84-85.

[25] See section 2.2.2 under *Tony Nicklinson*, and section 2.3.4.

[26] JA DiCamillo, 'A Comparative Analysis of the Right to Die in the Netherlands and the United States after Cruzan: Reassessing the Right of Self-Determination' (1992) 7(4) Am.U.Int'l L.Rev. 807. See section 3.3.2 for the 'right to self-determination'.

[27] Postma case, *Rechtbank Leeuwarden* [District Court Leeuwarden] 21 February 1973 reported in *Nederlandse Jurisprudentie* 1973 nr183: 558 [Lagerway W(tr), 'Euthanasia Case Leeuwarden-1973' (1988)3 Issues in Law and Medicine 429,439-442]. The Dutch cases cited in this section have been reported in Dutch, and their citation relies on a translation.

[28] ibid 442.

hastened death. Such medical decisions with a 'double effect' have also been legally endorsed by the English courts.[29]

The 1981 *Wertheim* case established that only physicians are allowed to participate in assisted deaths in the Netherlands. In the *Wertheim* case, a person who was not medically trained assisted in the suicide of a 67-year-old woman suffering from various medical conditions.[30] The District Court at Rotterdam recognised the patient's right to self-determination and established a set of criteria for assisted suicide to be justified. The criteria included that i) the patient had a voluntary desire to die, ii) the patient had experienced unbearable physical or mental suffering, iii) the patient was aware of treatment alternatives, iv) there was no other reasonable solution, and v) a physician was involved in the assisted death.[31] The Court found the person who had assisted the suicide guilty under Article 294 of the DPC, and imposed a six months conditional prison sentence which was subject to a one year probationary period, and two weeks of house arrest.

In 1984, the Dutch Supreme Court in the case of *Schoonheim*, not only endorsed the defence of necessity in cases of physician-assisted death, but also approved of a set of 'due care' criteria which had been issued by the KNMG.[32] The case involved a 95-year-old woman whose health was deteriorating due to an illness. Upon her repeated requests, her physician performed euthanasia. The Supreme Court overturned the physician's conviction, holding that the lower courts had failed to consider whether there had been a conflict of duties.[33] The question according to the Supreme Court was whether, according to responsible medical opinion measured by the prevailing standards of medical ethics, a situation of necessity had existed.[34] The Supreme Court's decision was influenced by the KNMG, which had not only published a set of 'due care' criteria that defined the circumstances in which Dutch physicians could perform euthanasia,[35]

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[29] See sections 2.3.1 and 3.3.6.

[30] Wertheim case, *Rechtbank Rotterdam* [District Court of Rotterdam] 1 December 1981 reported in *Nederlandse Jurisprudentie* 1982 nr63: 223. [J Griffiths et al(trs),*Euthanasia and Law in the Netherlands* (Amsterdam University Press 1998) 59].

[31] The remaining criteria were i) suffering and the voluntary desire to die being continuous; ii) the death does not inflict unnecessary suffering on others; iii) the decision to terminate life may not be taken by one person; iv) and the decision has to be made carefully.

[32] Griffiths (n30) 322-28.

[33] Schoonheim case (n23) 452.

[34] ibid 453.

[35] (1) voluntariness on the patient's part; (2) a well-considered request; (3) stability of desire; (4) unacceptable suffering; and (5) collegial consultation: KNMG, *Standpunt Inzake Euthanasie* ['Standpoint on Euthanasia'](n19).

but had also advised the Court that in a situation of necessity, euthanasia could be justified.[36]

It is submitted that the Supreme Court, by referring to and relying on the KNMG, deferred on the legal and ethical issue of assisted death to the medical profession.[37] This is similar to the practice by English courts of relying on medical assessments when determining whether life-sustaining treatment should be withdrawn or withheld from incompetent patients in their best interests, as discussed in Chapters Two and Four. Further, the Supreme Court's reliance on responsible medical opinion coincides with the application of the *Bolam* test[38] in Bland's case. As Lord Keith's judgment in *Bland* states: 'A medical practitioner is under no duty to continue to treat…a patient where a large body of informed and responsible medical opinion is to the effect that no benefit at all would be conferred by continuance.'[39] As discussed in Chapters Two and Three, neither the English courts nor the medical profession in England and Wales are in favour of assisted death in any form. Similarly, the DPP's prosecuting policy on assisted suicides deters physicians from providing any suicide assistance to patients.[40]

In 1994, the Dutch Supreme Court addressed the issue of non-somatic (non-physical) suffering in the case of *Chabot*.[41] The physician in Chabot's case supplied lethal drugs to a patient who did not suffer from any diagnosable medical condition, but had recently lost both her sons and divorced her husband.[42] She was described by the Supreme Court as suffering a 'depression in a narrower sense without psychotic characteristics, in the context of a complicated grieving process'.[43] The Court held that 'the wish to die of a person whose suffering is psychic can be based on an autonomous judgement', and that psychological suffering alone may satisfy the 'due care' criteria for assisted death as laid down in *Schoonheim*.[44] The Court, however, reversed the earlier acquittal of the lower court. The physician was found guilty of assisted suicide as he had not consulted

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[36] C Gomez, *Regulating Death: Euthanasia and the Case of the Netherlands* (Free Press 1991) 37-38.

[37] J Belian, 'Comment, Deference to Doctors in Dutch Euthanasia Law' (1996)10 Emory Int'l L.Rev. 255,257.

[38] See ch4 n18.

[39] Bland's case (ch1 n12) 858-59.

[40] DPP's Policy (ch1 n34) para43(14).

[41] Griffiths (n30) 329-40. Chabot case, *Hoge Raad (Strafkamer)* [Supreme Court (Criminal Division)] no 96.972, 21 June 1994 reported in *Nederlandse Jurisprudentie* 1994 nr656 [J Griffiths (tr), 'Assisted Suicide in the Netherlands: The Chabot Case' (1995)58 Modern Law Review 232].

[42] Chabot case (ibid).

[43] J Keown, 'Physician-Assisted Suicide and the Dutch Supreme Court' (1995)111 LQR 394,395.

[44] Griffiths (n30) 81,334-35.

an independent medical expert, which was held to be an essential requirement in cases of non-somatic suffering.[45] Nevertheless, no punishment was imposed on the physician.

Leenen argues that an independent medical expert would have been necessary for the patient in *Chabot*, as there may have been a realistic alternative treatment to alleviate the patient's psychological suffering.[46] Further, some Dutch commentators argued that the patient would not have been in a state of 'unbearable suffering' if a potentially effective treatment option had been refused by her.[47] Smies observes that *Chabot* represents a significant extension in the law, and indicates the Dutch courts' willingness to rely on 'personal autonomy'[48] and the 'right to self-determination' to justify assisted deaths in cases of psychological suffering.[49] It is submitted that in cases such as *Chabot*, patients could be vulnerable[50] due to depression and grief. Such depression[51] may impair a person's competence, and thus their decision-making capacity when requesting assisted suicide.

According to Michael and Tannock's definition of 'health-related quality of life' (discussed in Chapter Four), the patient's psychological suffering in *Chabot* would have related to her general health.[52] In this regard, the patient's assisted death may have been justified. However, it may forcefully be observed that the patient's quality of life would not have been health-related since the condition involved hopelessness, sorrow, or grief caused by death rather than an apparent or identifiable medical condition.

Despite the *Chabot* ruling that psychological suffering alone could satisfy the 'due care' criteria for assisted death, in 2003, the Supreme Court in the case of *Sutorius*[53] held that it was not lawful for a physician to assist death to simply relieve a patient of unbearable existential suffering.[54] In *Sutorius*, a physician had assisted the suicide of an 86-year-old patient who was suffering from physical decline, and struggled with his 'pointless and

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[45] ibid 337-38.

[46] HJJ Leenen, 'The Development of Euthanasia in the Netherlands' (2001)8 Eur J Health L 125,127.

[47] S Gevers and J Legemaate, 'Physician Assisted Suicide in Psychiatry: An Analysis of Case Law and Professional Options' in DC Thomasma et al(eds), *Asking to die: Inside the Dutch Debate about Euthanasia* (Kluwer Academic Publishers 1997) 77,85.

[48] See section 3.3.4.

[49] JT Smies, 'The Legalization of Euthanasia in The Netherlands' (2003-2004)7 Gonzaga J.Int'l.L.

[50] See section 3.4.6.

[51] See section 3.4.6 under *The depressed*.

[52] Michael, Tannock (ch4 n144).

[53] Brongersma|Sutorius case, *Hoge Raad (Strafkamer)* [Supreme Court (Criminal Division)] 24 December 2002 reported in *Nederlandse Jurisprudentie* 2003 nr167.

[54] T Sheldon, '"Existential" Suffering not a Justification for Euthanasia' (2001)323 BMJ 1384.

empty existence'.[55] The patient had also felt socially isolated, as all his friends and relatives had died.[56] The Supreme Court upheld the conviction for euthanasia. However, no punishment was imposed on the physician. The Court held that:

> a doctor who assists in suicide in a case in which the patient's suffering is not predominantly due to a "medically classified disease or disorder", but stems from the fact that life has become meaningless for him, acts outside the scope of his professional competence.[57]

The case of *Sutorius* made it clear that a patient's unbearable suffering had to be due to a medically classifiable cause, either physical (somatic) or psychiatric.[58] As De Vries rightly argues, although a physician must consider all types of suffering, including existential suffering, they are not specialists in hopeless despair, loneliness, or existential suffering caused by the inability to adapt to a new situation.[59] As was established in Chapter Four, existential suffering would affect one's quality of life in a global wider sense beyond being a mere medical condition.

It is concluded that the early history of Dutch jurisprudence on euthanasia and assisted suicide shows that, i) even when physicians have been found guilty of euthanasia or assisted suicide, the courts have been either reluctant or lenient in sentencing,[60] ii) there has been a judicial deference to the prevailing standards of medical ethics, iii) there has been a willingness by the courts to extend the 'due care' criteria, e.g. the inclusion of non-somatic suffering, and iv) the influence of self-determination and personal autonomy has been strong.[61]

5.2.2 *The Dutch Act*

In 2001, the Dutch Act amended Articles 293 and 294 of the DPC. The amendments allow physicians to perform euthanasia or assist suicide provided they comply with a set of 'due care' criteria. These 'due care' criteria are that the physician must (i) be satisfied

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[55] Keown (n24) 109-10.

[56] Sheldon (ch4 153).

[57] Griffiths (ch4 n152) 37.

[58] Sheldon (ch4 n150).

[59] de Vries (ch4 n151) 387,390.

[60] English courts have also demonstrated similar leniency with doctors who have had an equally active role in hastening the deaths of their patients. See section 2.3.1 and section 2.2.3 under *Healthcare professionals*.

[61] Smies (n49) 27.

that the patient's request is voluntary and well considered; (ii) be satisfied that the patient's suffering is unbearable and there is no prospect of improvement; (iii) inform the patient of their condition and further prognosis; (iv) discuss the situation with the patient and come to a joint conclusion that there is no other reasonable solution; (v) consult an independent physician who must examine the patient and confirm in writing that the attending physician has satisfied the 'due care' criteria and; (vi) exercise due medical care and attention in terminating the patient's life or assisting in their suicide.[62]

It is submitted that the 'due care' criteria in the Dutch Act focus on a patient's autonomous request to die, and on their health-related quality of life.[63] Nys cogently argues that the requirement of 'unbearable suffering' is based on the patient's own experience, thus this is a subjective assessment of suffering.[64] However, the related requirement that 'there is no prospect of improvement', is most likely an objective assessment by physicians. This requires a professional medical judgement to confirm that the patient's condition is irreversible.[65]

Hendin argues that, prior to the Dutch Act, consulting physicians were likely to be colleagues of the attending physician, and thus their supportive evaluations were likely to be a formality.[66] He states that consulting physicians 'seemed to be facilitators of the process rather than independent evaluators of the patient's situation…easing the doubts of physicians who were uncertain whether to go forward with euthanasia'.[67] To address this concern, today, a state-funded programme called 'Support and Consultation on Euthanasia in the Netherlands' ('SCEN') ensures that suitably qualified physicians are available in the Netherlands to give expert advice on assisted death, and to act as independent consulting physicians. To be accredited as a SCEN physician, a physician must complete training which includes legal frameworks, ethical issues, patient

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[62] *Wet toetsing levensbeëindiging op verzoek en hulp bij zelfdoding van 12 april 2001* [Termination of Life on Request and Assisted Suicide (Review Procedures) Act of 12 April 2001] Stb 2001 194 ('Dutch Act') sub-s 2(1).

[63] See section 4.4.2 under *Health-related quality of life*.

[64] H Nys, 'A Presentation of the Belgian Act on Euthanasia against the Background of Dutch Euthanasia Law' (2003)10 Eur J Health L 239,247.

[65] ibid 247.

[66] H Hendin, *Seduced by Death: Doctors, Patients, and the Dutch Cure* (WW Norton, 1997).

[67] H Hendin, 'Euthanasia Consultants or Facilitators?' (1999)170 Med J Aust 351.

communication and the process for completing a consultation report.[68] This ensures that all consultation reports meet a consistent nationwide standard.

As there are many cases of assisted suicide that fail,[69] the ‘due care’ criterion which requires physicians to ‘exercise due medical care and attention’ addresses concerns on completion and complications when lethal medication is administered.[70] In a study conducted in 2000, Groenewould et al found that almost one in five cases that started out as an assisted suicide ended with the physician administering a lethal injection because of complications:

> In most of these cases, the patient did not die as soon as expected or awoke from coma, and the physician felt compelled to administer a lethal injection because of the anticipated failure of the assisted suicide. In some cases, the physician administered a lethal injection because the patient had difficulty swallowing the oral medication, vomited after swallowing it, or became unconscious before swallowing all of it.[71]

Additionally, Griffiths et al argue that the requirement for physicians to ‘exercise due medical care and attention’ requires a physician to either stay with the patient continuously or be immediately available until the patient dies.[72] It is accepted that the existence of the Dutch *huisartsen* (family-care physicians) helps ensure that the physician attends to the patient and addresses all their needs until the time of death. In a 2008 study by Lindemann and Verkerk, it was found that an estimated 70% of physicians who assist deaths in the Netherlands are *huisartsen*.[73] Such physicians have a continuing and meaningful relationship with their patients. The requirement for physicians to ‘exercise due medical care and attention’ helps ensure that the lethal medication used remains under the control of the physician until the patient’s death and thus avoids any possible misuse or abuse.[74]

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[68] *Steun en Consultatie bij Euthanasie in Nederland* [Support and Consultation on Euthanasia in the Netherlands]. KNMG, *Opleiding en werken als SCEN-arts* [Training and work as SCEN physician] <http://knmg.artsennet.nl/Diensten/SCEN/Opleiding-en-werken.htm> accessed 31 December 2013.

[69] Keown (ch2 n389).

[70] JH Groenewoud et al, ‘Clinical Problems with the Performance of Euthanasia and Physician-Assisted Suicide in the Netherlands’ (2000)342 N Engl J Med 551,554-555.

[71] ibid 554-555.

[72] Griffiths (n30) 106.

[73] H Lindemann and M Verkerk, ‘Ending The Life of a Newborn, The Groningen Protocol’ (2008)38(1) Hastings Cent.Rep 42.

[74] Groenewoud (n70) 554-555.

Physicians are required to report the cause of death to the municipal pathologist.[75] After an examination of the patient's body, the municipal pathologist sends a report to one of five Regional Review Committees ('RRCs').[76] The RRCs assess whether physicians have acted in accordance with the 'due care' criteria. The RRCs may request physicians to supplement their medical reports with additional information to ensure a proper assessment.[77] The systematic feedback from the RRCs to physicians controls the practice of euthanasia and assisted suicide, and engenders the appropriate level of care needed for a lawful assisted death.[78] Only if a physician is found to have failed to comply with the 'due care' criteria, would an RRC report the case to the public prosecution authorities.[79] The RRCs publish a summary of their findings in an annual report[80] for the Minister of Health, Welfare and Sport, and the Minister of Justice who in turn report to Parliament. The Dutch Act relies on these annual reports by the RRCs to detect any abuse in the procedures.[81] As argued by Smets et al, the annual reports improve public oversight of the Dutch Act, evaluate its implementation, and assist in making suitable amendments to the law on assisted death.[82]

The 1990 Remmelink Report[83] found that euthanasia as a last resort with 'no other reasonable solution' was often interpreted to include cases where palliative care[84] treatment could have alleviated the patient's suffering, but where that treatment option had simply been declined by the patient.[85] The Dutch law on assisted death thus gives emphasis to respect for personal autonomy[86] and self-determination,[87] as a patient is free to refuse palliative care and insist on assisted death. Keown, however, argued that

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[75] *Wet op de lijkbezorging van 7 maart 1991* [Burial and Cremation Act of 7 March 1991] Stb 1991 130 sub-s 7.2.

[76] ibid s 10. The municipal pathologist examines the patient's body to determine how the euthanasia was performed and which substances were used.

[77] Nys (n64) 252.

[78] T Smets et al, 'The Medical Practice of Euthanasia in Belgium and The Netherlands: Legal Notification, Control and Evaluation Procedures' (2009)90 Health Policy 181,187.

[79] Dutch Act (n62) s 8, sub-s 9(2)(a).

[80] ibid s 109.

[81] ML Allen, 'Crossing the Rubicon: The Netherlands Steady March Towards Involuntary Euthanasia' (2005-2006)31 Brooklyn J.Int'l L 535,572.

[82] Smets (n78) 185.

[83] The first of three Dutch government-commissioned nationwide studies of medical decisions concerning end-of-life.

[84] See section 3.4.3.

[85] PJ van der Maas et al, 'Euthanasia and Other Medical Decisions Concerning the End of Life' (1991) 338 Lancet 669 ('The Remmelink Survey').

[86] See section 3.3.4.

[87] See section 3.3.2.

euthanasia in the Netherlands has often been used as an alternative to palliative care.[88] In 2002, Keown observed that approximately 40% of Dutch physicians indicated that '[a]dequate alleviation of pain and/or symptoms and personal care of the dying patient make euthanasia unnecessary'.[89] Although the Dutch Act does not require palliative care measures to be explored, the RRCs' annual reports stress that physicians should always make the patient aware of palliative care options for relieving suffering.[90] Nevertheless, the RRC members – who consist of a lawyer, a physician and an ethicist – may not have the relevant knowledge and expertise in palliative care, and thus may not be able to assess whether physicians have explored all reasonable options before resorting to euthanasia.[91]

Since the early 1990s, procedures for reporting euthanasia and assisted suicide in the Netherlands have been evaluated and revised several times to increase the rate of reporting by physicians,[92] and control the practice.[93] Smets et al note that Dutch experience has been that physicians are more likely to report their cases to the medical profession rather than the public prosecution authorities. They are more open to review when they did not face the threat of immediate investigation.[94] In this regard, the RRCs have been successful as a buffer between physicians and the authorities.[95] Smets et al observe that physicians generally regard the RRCs as supportive, and that their existence provides a strong motivation for physicians to report their cases.[96] This is

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[88] J Keown, 'Euthanasia in the Netherlands: sliding down the slippery slope?' in *Euthanasia Examined: Ethical, Clinical and Legal Perspectives* (J Keown ed, CUP 1995) 281.

[89] Keown (n24) 111.

[90] '*Jaarverslag* [Annual Report]' (*Regionale toetsingscommissies euthanasie* [Regional Euthanasia Review Committees]) <www.euthanasiecommissie.nl/overdetoetsingscommissies/jaarverslag> accessed 19 June 2014.

[91] Hendin (n14) 241.

[92] The reporting rates have gradually increased in the Netherlands. From as low as 18% in 1990,[92-1] the reporting rates have increased to 41% in 1995,[92-2] 54% in 2001,[92-3] and further to 80.2% in 2005.[92-4]

> [92-1] The Remmelink Survey (n85).
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> [92-2] PJ van der Maas et al, 'Euthanasia, Physician-Assisted Suicide, and Other Medical Practices Involving the End of Life in the Netherlands, 1990-1995' (1996)335 N Engl J Med 1699 ('The van der Maas Survey').
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> [92-3] BD Onwuteaka-Philipsen et al, 'Euthanasia and Other End-of-Life Decisions in the Netherlands in 1990, 1995, and 2001' (2003)362 Lancet 395 ('The Onwuteaka-Philipsen Survey').
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> [92-4] A van der Heide et al, 'End-of-Life Practices in the Netherlands under the Euthanasia Act' (2007)356(19) The N Engl J Med 1957 ('The van der Heide Study').

[93] Onwuteaka-Philipsen (ch1 n73).

[94] Smets (n78) 186.

[95] G van der Wal et al, 'Evaluation of the Notification Procedure for Physician-Assisted Death in the Netherlands' (1996)335(22) New Engl J Med 1706, 1710.

[96] Smets (n78) 186.

supported by an increase in the physician reporting rate in the Netherlands from 18% in 1990 (prior to the RRCs) to 80.2% in 2005.[97]

Smets et al observe that to ensure that euthanasia and assisted suicide are adequately regulated under the Dutch Act, controls were included in the form of reporting procedures for physicians, checks by the multi-disciplinary RRCs, and an assessment by Parliament.[98] However, there may not be effective control of assisted death in the Netherlands as the Dutch Act relies exclusively on physician self-reporting.[99] As Lewis cogently argues, physician reports may be fabricated so as to better fit the 'due care' criteria.[100]

The 1995 Van der Maas study[101] found depression to be the predominant symptom in 3% of all patients who died by euthanasia or assisted suicide between 1990 and 1995.[102] As argued by Hendin, physicians are generally unable to assess when patients have psychiatric disorders that may be interfering with their judgement.[103] In a 2005 study on euthanasia and depression among terminally ill cancer patients, it was found that cancer patients with a depressed mood were four times more likely to request euthanasia.[104] It is submitted that as a mental health evaluation is not mandatory under the Dutch Act, vulnerable patients[105] suffering from a psychiatric or psychological disorder may go undetected and untreated under the Dutch Act.

The Dutch Act is available to patients who are experiencing the early onset of dementia. The first reported case of an assisted suicide which involved a patient suffering from dementia, was in 2004. The patient, who had been diagnosed with dementia three years earlier, stated that he did not want to endure the full course of his illness. He accordingly requested an assisted suicide.[106] In its 2004 annual report, the RRCs noted that suffering in the early stages of dementia from the unacceptable prospect of further

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[97] The van der Heide Study (n92-4).

[98] Smets (n78) 182.

[99] Allen (n81) 572.

[100] Lewis (ch1 n177) 203.

[101] The second Dutch government commissioned nationwide study.

[102] The van der Maas Survey (n92-2).

[103] Hendin (n14) 237.

[104] ML van der Lee et al, 'Euthanasia and Depression: A Prospective Cohort Study Among Terminally Ill Cancer Patients' (2005)23 J Clinical Oncology 6607.

[105] See section 3.4.6.

[106] *Regionale toetsingscommissies euthanasie: Jaarverslag 2004* [Regional Euthanasia Review Committees: Annual Report 2004] (English edn) ('2004 RRC Annual Report').

loss of dignity amounted to 'suffering hopelessly and unbearably'. Nevertheless, the RRCs acknowledged that:

> it is not always possible to perform euthanasia in accordance with the due care criteria when the patient in question is suffering from Alzheimer's disease ... careful consideration will have to be given to all the facts and circumstances.[107]

The extension of the Dutch law on assisted death to patients suffering from the early onset of dementia may support concerns of a 'slippery slope' in the Netherlands. This will be considered in Chapter Six.

The Dutch Act also expanded the scope of lawful euthanasia and assisted suicide by providing that if a person becomes legally incompetent, but before reaching this state had written an advance declaration requesting that their life be terminated under particular circumstances, then their physician may comply with that request.[108] This is in contrast to English law, where advance directives are restricted to the refusal of life-sustaining treatment.[109] Considering that the 'due care' criteria apply equally to advance declarations, it was originally uncertain whether these advance declarations would have effect in practice. As noted by Griffiths in 2001, 'since the ['due care' criteria] continue to apply - in particular the requirement of unbearable suffering - it is doubtful the provision [on advance declarations] will have much practical effect'.[110] Yet, in 2004, the Dutch Minister of Justice subsequently endorsed the legality of advance declarations of incompetent patients for medical conditions such as dementia, including Alzheimer's disease. He accepted that a person suffering in the early stages of dementia may experience 'unbearable and hopeless suffering' due to the 'fear of further deterioration and the risk of not being able to die with dignity'.[111]

It is submitted that advance declarations under the Dutch Act effectively enable competent patients to extend their autonomy, to make decisions concerning their death into periods when they are no longer competent. Nevertheless, a request in an advance

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[107] T Sheldon, 'Dutch approve euthanasia for a patient with Alzheimer's disease' (2005)330 BMJ 1041. See: 2004 RRC Annual Report (ibid).

[108] Dutch Act (n62) sub-s 2(2).

[109] See section 2.3.3 under *Advance decisions*.

[110] J Griffiths, 'Important Changes in Euthanasia Law' (2001)4 Newsletter MBPSL: Regulation of Medical Behaviour that Potentially Shortens Life (Newsletter of the MBPSL Research Group, University of Groningen, The Netherlands).

[111] Griffiths (ch4 n152) 46.

declaration may still not always satisfy the ‘due care’ criterion for a ‘voluntary and well-considered request’ because the request is not contemporaneous with, and may not be evidence of, the patient’s wishes at the time that the advance declaration is carried out. As such, Dutch physicians may sometimes be reluctant to entertain advance declarations for euthanasia or assisted suicide from those suffering from dementia. This is demonstrated in Rurup et al’s 2004 study on physicians’ experiences with patients suffering from dementia. They found that approximately 2,200 patients with advance declarations requesting euthanasia after the onset of dementia die annually, having been treated by a physician who knows about the declaration. Although in 76% of cases, compliance with the advance declaration is discussed, euthanasia is seldom performed.[112] This extension of the Dutch law on assisted death to incompetent patients through their advance declarations, for medical conditions such as dementia (including Alzheimer’s disease), may further support ‘slippery slope’ concerns. This will be discussed in Chapter Six.

Some minors are regarded as having decision-making capacity in the Netherlands and are therefore not excluded under the Dutch Act. Section 2(3) provides that minors aged between 12 and 16 years who have a reasonable understanding of their interests, may request for assisted death and the physician may comply provided the minor’s parents or guardian agree. Minors between 16 and 18 who have a reasonable understanding of their interests may obtain euthanasia or assisted suicide without parental consent, although their parents must be involved in the decision-making process.[113] Cohen-Almagor cogently argues that this Dutch provision overestimates the capacity of minors to evaluate the meaning and consequences of a request to die. He says that by giving minors the opportunity to make such requests, it places a huge responsibility on young people and thus may disturb society’s confidence in the relationship between physicians, parents, and children.[114] Jochemsen argues that unless Dutch society is prepared to give minors the right to do everything else in life that an adult can do,

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[112] ML Rurup et al, ‘Physicians’ Experiences with Demented Patients with Advance Euthanasia Directives in the Netherlands’ (2005)53 J Am Geriatrics Society 1138.

[113] The law is similar in England and Wales, in the context of the maturity of minors in making treatment decisions. Under English law by statute, at 16 years it is legally presumed that minors have the ability to make decisions about their own care, and they may also be presumed to have the capacity to consent to treatment.[113-1] However, at common law, a minor under 16 may only have the capacity to consent to treatment, depending on their maturity and ability to understand what is involved. This capacity will depend on their ability to understand and weigh up options.[113-2]

[113-1] GMC, *0 – 18 years: guidance for all doctors* (2007) para25; Family Law Reform Act 1969 s 8.

[113-2] GMC, *0 – 18 years: guidance for all doctors* (ibid) para25; *Gillick v West Norfolk and Wisbech AHA* [1986] AC 112.

[114] R Cohen-Almagor, ‘Why the Netherlands?’ (2002)30 J.L.Med.& Ethics 95.

giving them the right to end their life seems out of place.[115] It is contended that minors are particularly vulnerable and often rely on others for their well-being.[116] The capacity to make such grave decisions concerning death may be affected by their physical and emotional development and by changes in their health and treatment.[117] It is submitted that the provisions relating to minors in the Dutch Act are further instances of reinforcing an individual's right to autonomy.[118] As will be discussed in Chapter Six, the extension of the Dutch law on euthanasia and assisted suicide to minors between the ages of 12 and 16 years may provide support for 'slippery slope' concerns.

It is submitted that as Dutch physicians have been entrusted with carrying out the practice of 'physician-assisted death', Dutch society has accepted assisted death as part of overall medical practice involving end-of-life medical decisions. The adoption of the KNMG's 'due care' criteria by the Dutch courts and their subsequent codification in the Dutch Act shows the level of influence which the medical profession has had on the law on euthanasia and assisted suicide in the Netherlands. As de Vries forcefully argues:

> [T]he [Dutch] law allows for a medical exception [to Articles 293 and 294 of the Penal Code] because only doctors are allowed to entertain a request for euthanasia [and assisted suicide]…considerations about the request[,] specifically whether the patient's suffering has been hopeless and unbearable[,] are medical or clinical considerations and considerations upon which the courts must rely.[119]

Similarly, Gunning cogently argues that, 'Many people think that legalising euthanasia will make [patients] autonomous. But, in fact, it is the doctor…who decides when life should be ended'.[120] It is argued that the 'due-care' criteria in the Dutch Act may be as much a reflection of medical paternalism[121] as of patient autonomy, due to their focus on a physician's compliance with the law. Likewise, in England and Wales, English courts

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[115] H Jochemsen, 'The Legalization of Euthanasia in the Netherlands' (2001)1 Ethics& Medicine 17.

[116] See GMC, *0 – 18 years: guidance for all doctors* (n113-1).

[117] ibid para 26.

[118] Smith (ch3 n271).

[119] de Vries (ch4 n151) 378.

[120] KF Gunning, 'Why Not Euthanasia' (*Compassionate Healthcare Network,* 9 October 2004) <www.chninternational.com/Gunning%202006.html> accessed 19 June 2014.

[121] See section 3.3.8.

rely on medically paternalistic assessments of an incompetent patient's best interests when deciding whether to withhold or withdraw life-sustaining treatment from them.[122]

The Netherlands extended lawful euthanasia to include non-voluntary euthanasia,[123] when it made neonatal termination a lawful medical practice. The following section will consider neonatal termination in the Netherlands.

5.2.3 *Neonatal termination*

Neonatal termination has been taking place in the Netherlands since the late 1980s, and has been recognised as a lawful practice, provided that physicians act in accordance with accepted medical practice. As observed by Borst-Eilers, a 1987 survey conducted by the Dutch Paediatric Association ('DPA') found that all eight neonatology centres surveyed permitted neonatal termination. Five of the centres had a general policy of administering a lethal drug in exceptional cases, while the other three limited such practice to the 'dying phase'.[124]

The 1995 cases of *Prins* and *Kadijk,* concerning two critically ill and severely disabled infants, demonstrate a strong influence of medical paternalism[125] in neonatal termination.[126] The *Prins* case involved a three-day-old baby with spina bifida,[127] whilst the case of *Kadijk* involved a 24-day-old baby with trisomy 13.[128] As the infants in both cases had a limited life expectancy with suffering that could not be alleviated, at the explicit request of their parents, the infants' physicians ended their lives with lethal medication. In neither of these cases were the physicians found guilty of murder. Instead, in both cases, the courts accepted the defence of necessity and found the physicians to have acted according to sound medical opinion and within the norms of medical ethics.[129] It is contended that the decision to end the lives of the infants in *Prins*

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[122] See section 4.3.

[123] 'Non-voluntary euthanasia' (text to ch1 n98).

[124] E Borst-Eilers, 'Euthanasia in the Netherlands: Brief Historical Review and Present Situation' in RI Misbin (ed), *Euthanasia: The Good of the Patient, the Good of Society* (University Publishing Group 1992) 55,58.

[125] See section 3.3.8.

[126] Magnusson (ch2 n258) 1132.

[127] Prins case: *Rechtbank Alkmaar* [District Court of Alkmaar] 26 April 1995 reported in *Nederlandse Jurisprudentie* 1995 nr 602. On appeal: *Gerechtshof Amsterdam* [Court of Appeals at Amsterdam] 7 November 1995 reported in *Nederlandse Jurisprudentie* 1996 nr113.

[128] Kadijk case: *Rechtbank Groningen* [District Court of Groningen] 13 November 1995 reported in *Nederlandse Jurisprudentie* 1996 nr35. On appeal: *Gerechtshof Leeuwarden* [Court of Appeals at Leeuwarden] 4 April 1996 reported in TGR 1996/35.

[129] Griffiths (n30) 308,350-351.

and *Kadijk* was based on a paternalistic judgement of quality of life by the physicians.[130] Further, two national surveys of Dutch neonatal deaths during the periods August to November 1995[131] and August to November 2001,[132] both found an estimated 10 to 15 cases of neonatal termination annually. Of these, however, only three cases were being reported to the authorities per year on average.[133]

To improve reporting rates, the Groningen Academic Hospital introduced a set of guidelines for the neonatal termination of severely ill infants in December 2004.[134] The guidelines were called the *Groningen Protocol*. The *Groningen Protocol* was endorsed by the KNMG and adopted by the DPA as a national guideline in 2005.[135] By excusing cases of neonatal termination on the basis that they have complied with the *Groningen Protocol*, the Dutch public prosecution authorities have indirectly approved of the Protocol,[136] resulting in neonatal termination officially becoming a lawful practice in the Netherlands. In the same way, in England and Wales, the DPP's reluctance to prosecute 'compassionate' assisted suicide cases has led to the public perception that assisted suicides that meet the criteria stipulated by the DPP's Policy have been decriminalised.[137] The *Groningen Protocol* was given further validation in 2007, when a national review committee with multidisciplinary expertise[138] (similar to the RRCs) was set up to review all cases of neonatal termination to ensure that its requirements had been met.[139] There is a distinct difference between the law in the Netherlands and the law in England and Wales in respect of severely ill newborn infants. As LJ Taylor in the English case of *Re J* said:

> It cannot be too strongly emphasised that the court never sanctions steps to terminate life. That would be unlawful. There is no question of approving,

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[130] In England and Wales, a similar paternalistic judgement of quality of life has been applied in cases which involve the withholding or withdrawal of life-sustaining treatment from critically ill and severely disabled newborn babies. See section 4.3.1.

[131] A van der Heide et al, 'Medical End-of-Life Decisions Made for Neonates and Infants in the Netherlands' (1997)350 Lancet 251,253.

[132] Vrakking et al, 'Medical end-of-life decisions made for neonates and infants in the Netherlands, 1995–2001' (2005) 365 Lancet 1329, 1330.

[133] E Verhagen and PJJ Sauer, 'End-of-Life Decisions in Newborns: An Approach from the Netherlands' (2005)116 Paediatrics 736, 738.

[134] ibid 738.

[135] E Verhagen, 'End of life Decisions in Newborns in the Netherlands: Medical and Legal Aspects of the Groningen Protocol' (2006)25 Medical Law 399.

[136] Lindemann and Verkerk (n73).

[137] See section 2.2.4.

[138] Consisting of a legal expert, an ethicist, a neonatologist, a gynaecologist and a neurologist.

[139] Lindemann and Verkerk (n73).

> even in a case of the most horrendous disability, a course aimed at terminating life or accelerating death. The court is only concerned with the circumstances in which steps should not be taken to prolong life.[140]

The *Groningen Protocol* identifies three categories of newborns for whom physicians may perform neonatal termination — i) infants with no chance of survival, ii) infants who may survive after a period of intensive treatment, but would have a very poor quality of life, iii) infants with an extremely poor prognosis 'who do not depend on technology for physiologic stability and whose suffering is severe, sustained, and cannot be alleviated'.[141] The requirements of the protocol are that — i) the diagnosis and prognosis for the infant has to be certain, ii) the infant is experiencing hopeless and unbearable suffering, iii) the diagnosis, prognosis, and unbearable suffering has to be confirmed by an independent physician, iv) both parents have to give informed consent, and v) the procedure has to be performed in accordance with accepted medical standards.[142]

It is submitted that the requirements of the *Groningen Protocol,* where possible, have tried to parallel the 'due care' criteria in the Dutch Act. Consistent with the Dutch Act, a measure of unbearable suffering is applied to newborns under the *Groningen Protocol.* However, unlike the Dutch Act, the element of 'unbearable suffering' in relation to newborns is more of an objective assessment of quality of life by physicians. As argued by Kon, Dutch physicians are unable to accurately assess a newborn's suffering, and determine whether the burdens of living outweigh the benefits.[143] They would therefore be incapable of establishing whether death is in a newborn's 'best interests'. As will be discussed in Chapter Six, this extension of the Dutch law from voluntary euthanasia[144] to non-voluntary euthanasia[145] for newborns may also support 'slippery slope' concerns.

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[140] *Re J (A Minor)* (ch2 n236) 943.

[141] Verhagen and Sauer (n133) 736.

[142] Lindemann and Verkerk (n73).

[143] AA Kon, 'Neonatal Euthanasia Is Unsupportable: The Groningen Protocol Should Be Abandoned' (2007)28(5) Theoretical Medicine and Bioethics 453. Kon has indirectly expressed the same concerns of the Court of Appeal in the English case of *Re J (A Minor)* (ch2 n236), concerning the dangers of judging the child's quality of life from the outside and not from the perspective of the child.

[144] 'Voluntary euthanasia' (ch1 n7).

[145] 'Non-voluntary euthanasia' (text to ch1 n98).

5.2.4 *Summary for the Netherlands*

In conclusion, pursuant to the Dutch law on assisted death, a patient is required to be suffering unbearably, either physically or mentally, from a medical condition. To satisfy the requirement of ‘due medical care and attention’, a physician may be required to either stay with the patient continuously or be immediately available until the patient dies. This requirement not only addresses any complications during and immediately after an assisted death, but also avoids any possible misuse of the lethal medication supplied for assisted suicide, or abuse of the law. The existence of the *huisartsen* in the Netherlands also helps ensure that physicians address all the needs of their patients until the time of death. Further, to facilitate the Dutch Act, the SCEN network of physicians not only provides expert advice on assisted death, but also ensures the independence of consulting physicians. The RRCs also ensure that physicians comply with the ‘due care’ criteria. The Dutch Act includes safeguards in the form of reporting procedures for physicians, checks by the multi-disciplinary RRCs, and an assessment by Parliament. Nevertheless, there may not be effective control of assisted death in the Netherlands.

The Dutch Act relies exclusively on physician self-reporting which means there is potential for the fabrication of reports. Further, as there is no requirement for palliative care, euthanasia has often been used as an alternative to palliative care. Clinical depression in patients may also go undetected under the Dutch law, as there is no mandatory mental health evaluation of patients requesting an assisted death. Additionally; the Dutch Act has extended the law on assisted death to patients suffering from the early onset of dementia, minors, and to incompetent patients who have made advance declarations for medical conditions that include dementia and Alzheimer’s disease. These extensions to the Dutch law on assisted death not only raise concerns of a ‘slippery slope’, but also raise issues pertaining to the ‘due care’ requirement for a voluntary and well-considered request. Further, since 2005, neonatal termination has become lawful in the Netherlands with the approval of the *Groningen Protocol*. Thus, what started off as lawful voluntary euthanasia has now been extended to non-voluntary euthanasia. This extension no longer reflects the influence of autonomy in the Dutch law on assisted death, but rather the influence of medical paternalism.

5.3 Belgium

On 23 September 2002, the Belgian Act Concerning Euthanasia ('Belgian Act') came into force, making Belgium the second country in the world to legalise euthanasia.[146] The Belgian euthanasia law is based on the Dutch Act, but unlike the Netherlands, Belgium's progression towards legalisation was not supported by its medical profession.[147] As Belgium did not have the same permissive approach towards euthanasia as the Netherlands, there was no case law or regulated practice addressing euthanasia prior to the Belgian Act.[148]

5.3.1 *Background*

Prior to proposals for a law to legalise euthanasia, there were hardly any physicians prosecuted for euthanasia[149] in Belgium.[150] This is despite a finding by a 1998 study of end-of-life medical practices by Belgian physicians, that an estimated 640 cases of voluntary euthanasia[151] (1.1% of all deaths) and no less than 1,796 cases of termination of life without the patient's explicit request (3.2% of all deaths) occurred in the Belgian region of Flanders[152] in 1998.[153] The study indicated that Belgian physicians (or at least those from the Flanders region) had developed a practice of non-voluntary euthanasia.[154] Van der Wal et al observed that physicians often participated in such a practice, in cases where the medical decisions had been delayed or deferred. In these cases, patients had

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[146] C Gastmans et al, 'Facing Requests for Euthanasia: A Clinical Practice Guideline' (2004)30 J Medical Ethics 212,212.

[147] Smets (n78) 182.

[148] F Mortier, L Deliens, 'The Prospects of Effective Legal Control of Euthanasia in Belgium: Implications of Recent End-of-Life Studies' in A Klijn et al (eds),*Regulating Physician Negotiated Death* (Elsevier 2001).

[149] The *Code Pénal* [Penal Code] ('Belgian Penal Code': 'BPC') does not recognise euthanasia as a separate criminal offence. However, a person who ends the life of another at their request (voluntary euthanasia) may be charged with manslaughter (art 393), murder (art 394) or poisoning (art 397).

[150] B Broeckaert, 'Belgium: Towards a Legal Recognition of Euthanasia' (2001)8 Eur J Health L 95,95.

[151] 'Voluntary euthanasia' (ch1 n7).

[152] Belgium consists of three regions — the northern Dutch-speaking region of Flanders with 58% of the Belgian population, the southern French-speaking region of Wallonia with 33%, and the capital region of Brussels with the remaining 9%. Both Flanders and Wallonia have their own regional parliaments. Linguistic and cultural differences between these regions have made nationwide studies difficult.

[153] L Deliens, F Mortier et al, 'End-of-Life Decisions in Medical Practice in Flanders, Belgium. A Nationwide Survey' (2000)356 Lancet 1806 ('the Deliens-Mortier Study').

[154] Belgian studies have tended to focus on Flanders, as death certificate statistics are not compiled in Wallonia: R Cohen-Almagor, 'Belgian Euthanasia Law: A Critical Analysis' (2009)35 J Medical Ethics 436. 'Non-voluntary euthanasia' is explained in text to ch1 n98.

become legally incompetent and were experiencing a condition that was unbearable, irreversible and painful.[155]

Nys argues that while the Dutch Act aimed to codify the 'due care' criteria which had already been developed by the courts in the Netherlands, the Belgian Act aimed mainly to regulate the conduct of physicians in end-of-life medical practices which had previously been uncontrolled. The Belgian Act, according to Nys, was intended to encourage patients to express a voluntary and explicit request for euthanasia, and physicians to abandon their previous practice of termination of life without request.[156] In 2007, Bilsen et al compared two identical nationwide death certificate studies on end-of-life medical decisions in Flanders — one conducted in early 1998 (when the legalisation process of euthanasia in Belgium started),[157] and the other in late 2001 (just before the Belgian Act took effect).[158] They noted that a shift in medical practices had indeed occurred between the two studies. 'Termination of life with the intention of ending a patient's life' decreased from 4.4% of all deaths in 1998 to 1.8% in 2001. Voluntary euthanasia decreased from 1.1% to 0.3%, and 'termination of life without request' decreased from 3.2% to 1.5%. 'The alleviation of suffering with an intention to shorten life' also decreased from 5.3% to 2.8%. During the lead-up period to legalisation in Belgium, the judiciary initiated a number of criminal investigations into physicians who had helped to end their patients' lives.[159] Bilsen et al conclude that a fear of prosecution among physicians was a reason for the decline in end-of-life medical decisions between 1998 and 2001. They also observe that, besides a fear of prosecution, a growing awareness of the right to self-determination[160] may have led to an increased expectation among patients of their participation in end-of-life decisions.

5.3.2 *The Belgian Act*

Euthanasia is defined in the Belgian Act as 'intentionally terminating life by someone

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[155] G van der Wal, 'Unrequested Termination of Life: Is it Permissable?' (1993)7 Bioethics 330.

[156] Nys (n64) 240.

[157] The Deliens-Mortier Study (n153).

[158] J Bilsen et al, 'Changes in Medical End-of-Life Practices During the Legalization Process of Euthanasia in Belgium' (2007)65(4) Soc Sci Med 803. For the 2001 study, see A van der Heide et al, 'End-of-Life Decision-Making in Six European Countries: Descriptive Study' (2003)362 Lancet 345.

[159] ibid 807.

[160] See section 3.3.2.

other than the person concerned, at the latter's request'.[161] Compliance with the Belgian Act is monitored by the multi-disciplinary Belgian Federal Control and Evaluation Commission ('CFCE'),[162] to which all cases of euthanasia must be reported.[163] The Belgian Act does not expressly include assisted suicide. Nevertheless, in its first biannual report, the CFCE accepted cases of assisted suicide as falling under the Belgian Act.[164] It is submitted that this inclusion of assisted suicide has led to a discrepancy in Belgian law. Suicide and assisted suicide are not recognised as criminal offences in the Belgian Penal Code ('BPC'). However, the BPC does provide that if anyone intentionally provides assistance in another's death,[165] then they may be prosecuted for either criminal negligence or failing to aid a person in grave danger.[166]

In order for an assisted death to be legal, the Belgian Act requires the patient to be in a medically futile condition of persistent and unbearable physical or mental suffering that cannot be alleviated, as a result of a serious and incurable disorder caused by illness or accident.[167] In an English context, this provision in the Belgian Act would cover most of the recent cases that have been highlighted in the debate on assisted death in England and Wales, from terminal illnesses like motor neurone disease, to non-fatal conditions such as multiple sclerosis, spinal cord injuries, and locked-in syndrome.[168] It is submitted that the provision concerning the patient's medical condition in the Belgian Act, is a 'quality of life' judgement. The 'persistent and unbearable physical or mental suffering' is based on a subjective assessment by the patient. However, as physicians have the required knowledge and skill, they apply an objective assessment to the 'serious and incurable disorder', which covers both somatic (physical) and psychiatric diseases. As noted by Nys, if a patient refuses treatment for a curable disease, they may remain in a state of unbearable suffering, but the disease will not amount to an incurable one.[169] A patient's refusal of potentially curative treatment will prevent them from

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[161] *Loi relative à l'euthanasie F 2002-2141 [C 2002/09590] du 28 Mai 2002* [Act Concerning Euthanasia] MB 22 June 2002, 28515 ('Belgian Act') s 2.

[162] *Commission fédérale de contrôle et d'évaluation de l'euthanasie* [Federal Control and Evaluation Commission].

[163] Belgian Act (n161) s 5.

[164] *Commission fédérale de contrôle et d'évaluation de l'euthanasie*, *Premier rapport aux chambres législatives (2002–2003)* [CFCE, First Report to the Legislative Chamber (2002-2003)] 13-14. See also: P Lewis, 'Assisted Dying Regimes, Briefing Note to the End of Life Assistance (Scotland) Bill Committee'.

[165] BPC (n149) art 422 bis.

[166] Broeckaert (n150) 95.

[167] Belgian Act (n161) s 3.

[168] See section 2.2.2.

[169] Nys (n64) 247.

gaining access to the Belgian Act.[170] Thus, the Belgian law on euthanasia is not based on an absolute right to have one's personal autonomy respected.[171] Rather, such a right is qualified by the requirement for 'a serious and incurable disorder', which is determined by physicians.[172]

In its 2006/07 Report, the CFCE reported that the anticipation of a future coma, loss of independence, or progressive dementia could in themselves constitute 'a medically futile condition of persistent and unbearable mental suffering' 'here and now' that 'cannot be alleviated as a result of a serious and incurable disorder caused by illness' for the purposes of the Belgian Act.[173] This position was confirmed in its 2008/09 Report.[174] It is submitted that by extending the scope of 'mental suffering' to those who merely anticipate a future coma, loss of independence, or progressive dementia, such patients could be vulnerable[175] under the Belgian Act. These patients may be unable to make a sound judgement due to depression, or may be coerced or pressured into requesting euthanasia. As will be discussed in Chapter Six, this extension in the law may provide support for 'slippery slope' concerns in Belgium.

Cohen-Almagor observes that the CFCE's position that 'the anticipation of progressive dementia by a patient could in itself constitute mental suffering' differs from its earlier view, that assisting patients with dementia to die was unlawful due to the uncertainty concerning a patient's competence.[176] It is submitted that the CFCE's position may be an attempt to promote personal autonomy under the Belgian Act. Patients with dementia may make a request for euthanasia during a 'lucid moment'. However, in cases of dementia it would be difficult to fulfil the requirements under the Belgian Act for 'competence' and a 'voluntary request'. The wishes of a patient at the time of assistance may differ from the wishes expressed by them during a 'lucid moment'.[177] To be certain of a patient's wishes at the time of assistance, euthanasia itself would have to be performed during such a 'lucid moment'. This is demonstrated by two high profile

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[170] ibid 246-247.

[171] See section 3.3.4.

[172] Nys (n64) 247.

[173] *Commission fédérale de contrôle et d'évaluation de l'euthanasie, Troisième rapport aux chambres législatives (2006–2007)*[CFCE, Third Report to the Legislative Chamber (2006-2007)].

[174] *Commission fédérale de contrôle et d'évaluation de l'euthanasie, Quatrieme rapport aux chambres législatives (2008–2009)*[CFCE, Fourth Report to the Legislative Chamber (2008-2009)].

[175] See section 3.4.6.

[176] R Cohen-Almagor, 'Euthanasia Policy and Practice in Belgium: Critical Observations and Suggestions for Improvement' (2009)(24)(3) Issues L.&Med. 187,209.

[177] ibid 208-209.

Belgian cases. The first was in 2006, where a physician performed euthanasia on 87-year-old Suzanne Roegiest, who had reportedly asked to be allowed to die during a 'lucid moment'.[178] The second involved the prominent Belgian author, Hugo Claus, in 2008. Claus, who was 78 years old, had been diagnosed with Alzheimer's, and was reported to have been lucid, when euthanasia was performed in the presence of his wife.[179]

Under the Belgian Act, a patient has to voluntarily make a repeated request for euthanasia, inclusive of a written request.[180] The physician is also required to discuss the request, health and life expectancy, and possible therapeutic and palliative[181] treatment available with the patient.[182] These discussions must be spread out over a reasonable period of time, to allow the physician to be certain of the persistence of the patient's suffering and the enduring character of the patient's request. It is accepted that this requirement would ensure that the patient is making an autonomous, informed, and well-considered request to die. As observed by Lewy, the Belgian medical profession is governed by the Belgian Order of Physicians ('BOP') and its *Code of Medical Deontology* ('*CMD*'). The BOP had initially opposed assisted death,[183] and Article 95 of the *CMD* prohibited physicians from assisting patients to die. However, the *CMD* was amended in March 2006 to complement the Belgian Act.[184] As noted by Bosshard et al, Articles 95-98 of the *CMD* now mention the duty of a physician, upon receiving a question from a patient on end-of-life decisions, to inform the patient of all possible options and provide any medical and moral assistance required.[185] This initial opposition by the BOP to assisted death is similar to the current opposition by the GMC and BMA in England and Wales.[186]

Under the Belgian Act, the physician is also required to consult an independent physician about the patient's request for euthanasia. As the societal focus in Flanders is

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[178] J Burgermeister, 'Doctor reignites euthanasia row in Belgium after mercy killing' (2006)332(7538) BMJ 382.

[179] 'Author Claus dies by euthanasia' (*BBC News*, 21 March 2008) <http://news.bbc.co.uk/2/hi/entertainment/7308618.stm> accessed 19 June 2014.

[180] Belgian Act (n161) s 3.

[181] See section 3.4.3.

[182] Belgian Act (n161) s 3.

[183] G Lewy, *Assisted Death in Europe and America: Four Regimes and Their Lessons* (OUP 2011).

[184] Like the CFCE, the BOP has accepted cases of assisted suicide as falling under the Belgian Act: P Lewis, 'Euthanasia in Belgium Five Years after Legalisation' (2009)16 Eur J Health L 125,127.

[185] Bosshard (n9).

[186] See section 3.3.3.

on ‘personal autonomy’ and ‘quality of life’,[187] requests for euthanasia in that region of Belgium are common.[188] To support these requests, a network of volunteer physicians called End of Life Information Forum (‘LEIF’)[189] was established in Flanders in 2003.[190] The LEIF network not only helps physicians find an independent physician who is specially trained and accessible for a formal consultation, but also offers a wide information and support forum for healthcare practitioners and patients who have questions about the end-of-life options.[191] The LEIF network is similar to the Dutch state-funded SCEN programme (discussed above). As with SCEN, LEIF consulting physicians undergo a similar training programme to ensure nationwide consistency of consultations and reporting.[192]

As with the Dutch Act, the Belgian Act does not require a mental health evaluation to assess whether a patient is suffering from depression or other psychiatric or psychological disorders. For this reason, patients whose judgement could be impaired by mental disorders may be vulnerable under the Belgian Act. In cases where death is not imminent (inclusive of terminal conditions), physicians are required to consult a second independent physician, who may either be a specialist in the patient’s disorder or a psychiatrist.[193] It is accepted that a second independent physician provides some assurance that the patient’s request is well-considered. However, this safeguard may not be effective in protecting vulnerable patients. If the second independent physician is a specialist in the patient’s disorder, they will not necessarily be able to detect or assess whether any potential depression or other mental disorder has influenced a patient’s decision to die. Further, if death is not imminent, euthanasia is only performed after a month has lapsed from the time of the written request. As discussed in Chapter Three, the desire for death fluctuates.[194] Thus, the one month ‘cooling off’ period allows a patient time to reconsider their decision, and provides vulnerable patients an opportunity to reassess their request.

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[187] See ch4.

[188] Cohen-Almagor (n154). Refer to n152 for the three regions of Belgium.

[189] *LevensEinde InformatieForum* [End of Life Information Forum].

[190] LEIF, a voluntary organisation funded by the Belgian government, was established in Flanders in 2003. An equivalent organisation, *Médecins EOL*, has been established in Wallonia.

[191] Y Van Wesemael et al, ‘Role and Involvement of Life End Information Forum Physicians in Euthanasia and Other End-of-Life Care Decisions in Flanders, Belgium’ (2009)44 Health Services Research 2180, 2181.

[192] *Wat heeft de opleiding tot LEIFarts te bieden*? [What is the training for LEIF doctors?] (*LEIF*) <www.leif.be/nl/professioneel/opleiding-leifartsen.html> accessed 31 December 2013.

[193] Belgian Act (n161) sub-s 3(3).

[194] See section 3.4.3.

The Belgian Act requires a patient to be conscious and competent when making a request for euthanasia.[195] However, as with the Dutch Act, an advance directive is also recognised by the Belgian Act. An advance directive is valid if it is drafted within five years prior to the patient becoming legally incompetent.[196] For a patient's request for euthanasia in an advance directive to be acted upon, they have to also be in a medically irreversible state of unconsciousness, and suffer from a serious and incurable disease caused by illness or accident. It is argued that due to the qualification of 'a medically irreversible state of unconsciousness' only patients in a PVS would be able to satisfy the requirements for an advance directive under the Belgian Act.[197] Unlike the Dutch Act, there is no requirement for 'unbearable suffering', as it is assumed that an incompetent patient in a 'medically irreversible state of unconsciousness' is incapable of experiencing suffering.[198] As with the Dutch Act, advance directives are regarded as an extension of personal autonomy. Nevertheless, as there can be a lapse of almost five years from the time an advance directive is made to the time a request is carried out, in some cases it may be doubtful whether an advance directive is a valid representation of a patient's request and wishes at the time of the euthanasia.

The Belgian Act also requires patients to be over the age of 18, or an 'emancipated' minor.[199] Nys notes that the emancipation of a minor may result either from marriage or from a declaration by a judge that the minor is competent to deal with their own personal affairs.[200] It is argued that the Belgian Act places tighter controls over minors than the Dutch Act. As with the Dutch Act, the inclusion of emancipated minors in the Belgian Act clearly demonstrates that the Belgian law on euthanasia is influenced by the ethical principle of personal autonomy. As concluded earlier, decisions involving minors need to be treated with caution as minors may be particularly vulnerable due to their physical and emotional development.

Physicians are required to report their cases of assisted death to the CFCE.[201] However, the reporting rates for euthanasia have been low in Belgium. According to Smets et al's

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[195] Belgian Act (n161) s 3.

[196] ibid s 4.

[197] Nys (n64) 249.

[198] ibid 249.

[199] Belgian Act (n161) s 3. cf. English law position, refer to n113.

[200] Nys (n64) 244.

[201] Belgian Act (n161) s 5, sub-s 6(2). The CFCE has 16 members, comprising physicians, legal academics or lawyers and those that deal with incurably ill patients, including four palliative care workers: JL Bernheim et al, 'Development of Palliative Care and Legalisation of Euthanasia: Antagonism or Synergy?' (2008)336 BMJ 866.

2010 study on the reporting rate in Flanders[202] between June and November 2007, the rate of reporting was only 52.8% based on a random sample of euthanasia cases.[203] In contrast, the Dutch reporting rate in 2005 was estimated at 80.2% (discussed above).[204] It is argued that the higher reporting rate in the Netherlands is due to the fact that there is greater acceptance of this procedural ‘reporting’ requirement within the medical profession. As discussed above, procedures for Dutch reporting have been amended several times, and the RRCs were specifically established to encourage physicians to report their cases. As there is more consensus between the medical profession and the RRCs, the Dutch reporting rates have gradually increased. As observed by Smets et al, the higher reporting rate in the Netherlands may be explained by the fact that the Dutch had two decades of relatively open euthanasia practice before the Dutch Act came into force, and a reporting procedure had been in place since the early 1990s. In contrast, bringing euthanasia into the open is a relatively new experience for Belgian physicians, as they have only been required to report cases since the Belgian Act came into force in 2002.[205]

Smets et al’s 2010 study found that in 76.7% of cases, the main reason for not reporting euthanasia was that Flemish physicians did not know that their medical practices in the circumstances of those cases had amounted to euthanasia.[206] Smets et al argue that this is because Belgian law does not specify which drugs and which dosages should be used to perform euthanasia and does not have uniform guidelines, such as those that exist in the Netherlands.[207] This lack of knowledge as to what amounts to euthanasia is not unique to Flemish physicians, as Smets et al noted in a separate 2010 study on euthanasia amongst patients dying at home in Belgium between 2005 and 2006.[208] Smets et al deduced from their study that, although the Belgian Act has converted a once covert practice by

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[202] As requests for euthanasia are more common in Flanders, the reporting percentage is higher than in Wallonia: Cohen-Almagor (n154).

[203] T Smets et al, ‘Reporting of Euthanasia in Medical Practice in Flanders, Belgium: Cross Sectional Analysis of Reported and Unreported Cases’ (2010)341 BMJ c5174, 4(Table 1).

[204] See text to n97.

[205] Smets (n203) 5.

[206] ibid 3.

[207] *KNMP* [207-1] *& KNMG, Richtlijn Uitvoering euthanasie en hulp bij zelfdoding* [Joint Directive: Implementing euthanasia and assisted suicide] (2012).

[207-1] *Koninklijke Nederlandse Maatschappij ter bevordering der Pharmacie (KNMP)* [Royal Dutch Society for the Advancement of Pharmacy]

[208] T Smets et al, ‘Euthanasia in Patients Dying at Home in Belgium: Interview Study on Adherence to Legal Safeguards’ (2010)60 Br J General Practice e163.

physicians into a more open and controlled one, the legalisation of euthanasia alone has not been sufficient to guarantee a regulated practice of euthanasia.[209]

The CFCE refers cases to the public prosecutor, if physicians have not met the requirements of the Belgian Act.[210] The CFCE is also required to present a summary report of euthanasia cases to Parliament biannually. Thus, as observed by Smets et al, the Belgian Act may be appraised and the law revised and developed further. Like the annual reports of the RRCs under the Dutch Act, the biannual reports of the CFCE amount to public disclosure of the practice of euthanasia in Belgium.[211] However, Lewis argues that the Dutch practice of publishing details of cases of euthanasia in the annual reports of the RRCs allows for greater insight into individual cases than the essentially statistical reports of the CFCE.[212]

In summary, control measures were included in the Belgian Act which were similar to provisions in the Dutch Act, in the form of physician self-reporting, a review by the multi-disciplinary CFCE and appraisals by Parliament.[213] These can ensure that euthanasia is properly regulated as a medical practice in Belgium. As noted by Smets et al, Belgium and the Netherlands both established multi-disciplinary review committees, as physicians in both countries preferred not to be examined by public prosecutors.[214] As discussed above in section 5.2.2, review committees function as a buffer between physicians and the public prosecution authorities, placing emphasis on information, accountability and transparency, rather than deterrence and punishment.[215] However, as persuasively argued by Smets et al, the existence of one central review committee in the form of the CFCE in Belgium, may provide better control and uniformity in the practice of euthanasia by physicians, than the five RRCs in the Netherlands.[216]

As the official data on the practice of euthanasia in Belgium is largely based on self-reporting (similar to the Netherlands),[217] this may not amount to an effective

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[209] ibid e169.

[210] Belgian Act (n161) s 8.

[211] Smets (n78) 185.

[212] Lewis (n184) 134.

[213] Smets (n78) 182.

[214] ibid 186.

[215] van der Wal (n95) 1710.

[216] Smets (n78) 186.

[217] Smets (n208) e164.

safeguard against abuse of the law. Physicians may be inclined to only report cases where due care has been exercised, or to report that their cases complied with the law regardless of the actual circumstances.[218] As will be discussed in Chapter Six, the disregard for the reporting requirements under the Belgian Act may support 'slippery slope' concerns.

The Belgian Palliative Care Act ('PCA 2002'), which was passed at the same time as the Belgian Act, requires every patient approaching the end-of-life to be able to benefit from palliative care.[219] Article 7 of the PCA 2002 specifically provides that every patient has the right to obtain information about palliative care possibilities from their treating physician. Although the Belgian Act does not include a mandatory requirement for a patient to actually receive palliative care, it does require physicians to discuss palliative treatment options with their patients. Additionally, a few months after the Belgian Act was passed, the Belgian Medical Disciplinary Board ('MDB') issued a set of guidelines endorsing the Belgian Act, and emphasising that palliative care must be exhausted as an option before resorting to euthanasia.[220] As a result, every Belgian hospital has a palliative care team, and palliative home care is available nationally.[221] In addition, as LEIF physicians are also trained in palliative care, physicians may consult them on possible palliative treatment for their patients.[222] The CFCE is also able to monitor the extent to which Belgian physicians have explored and exhausted palliative care treatment before resorting to euthanasia, since four of its 16 members are palliative care experts.[223] Further, a unique feature of healthcare practice in Belgium is that 70% of Belgian hospitals are Catholic healthcare institutions run by the Caritas network.[224] Gastmans et al note that the guidelines of the Ethics Committee of the Caritas network restrict euthanasia to the terminally ill. As such, healthcare institutions run by Caritas do not recognise 'absolute' patient autonomy in cases of euthanasia.[225] Caritas Flanders

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[218] RS Magnusson, 'Euthanasia: Above Ground, Below Ground' (2004)30(5) J Medical Ethics 441.

[219] *Loi relative aux soins palliatifs F 2002-3849 [C 2002/22868] du 14 Juin 2002* [Act Concerning Palliative Care] MB 26 October 2002, 49160 art 2. See section 3.4.3 for 'palliative care'.

[220] Conseil National de l'Ordre des Médecins, *Avis relatif aux soins palliatifs, à l'euthanasie et à d'autres décisions médicales concernant la fin de vie* [National Council of the BOP, 'Advice on palliative care, euthanasia and other medical end-of-life decisions'](March 2003) <www.ordomedic.be/fr/avis/conseil/avis-relatif-aux-soins-palliatifs-a-l%27euthanasie-et-a-d%27autres-decisions-medicales-concernant-la-fin-de-vie> accessed 21 November 2013.

[221] JL Bernheim and A Mullie, 'Euthanasia and Palliative Care in Belgium: Legitimate Concerns and Unsubstantiated Grievances' (2010)13(7) J Palliat Med 798.

[222] W Distelmans, S Bauwens, 'Palliative Care is more than Terminal Care' (2008)2 Belg J Med Oncology 16.

[223] Bernheim (n201).

[224] Lewy (n183) 75.

[225] Gastmans (n146).

oversees 65% of the general hospitals and 40% of nursing homes in Flanders.[226] Gastmans et al observe that:

> most ... Catholic healthcare institutions [in Flanders] consider ... [the requirement in the Belgian Act for physicians to discuss all possible palliative treatment with patients] to be insufficient, since in their view, not all [physicians] are familiar with the possibilities offered by various palliative care facilities ... they believe ... that euthanasia can only be justified when an obligatory consultation takes place with a palliative care expert.[227]

Thus, many Catholic hospitals in Flanders impose a palliative filter requirement to ensure that all palliative options are explored by terminally ill patients.[228]

It is concluded that the emphasis placed on palliative care treatment options for patients making end-of-life decisions in Belgium, and the extensive availability of palliative care resources, address the concerns of many whose needs can be met by adequate palliative care. The developments in palliative care at the time euthanasia was legalised in Belgium underscore the fact that euthanasia was intended to be an option of last resort. Smets et al's 2009 study of reported euthanasia cases between September 2002 and December 2007 notes that 'the proportion of euthanasia cases in which at least 1 palliative team was consulted remained stable over the years'.[229] It found that a palliative care specialist was consulted as the second independent physician in 12% of cases, and that palliative teams were consulted in 35% of cases.[230] The amount of overlap, in order to determine how many cases involved either a palliative specialist or team, was not stated. It is submitted that such low rates may be due to the fact that a palliative care consultation is not a mandatory requirement under the Belgian Act.

The CFCE noted in its 2006/07 biannual report, a view by some of its members that consultations beyond those that are legislatively required (such as the mandatory palliative consultation as required by Caritas Flanders discussed above) may constitute

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[226] Lewy (n183) 75.

[227] C Gastmans et al, 'Prevalence and content of written ethics policies on euthanasia in Catholic healthcare institutions in Belgium (Flanders)' (2006)76 Health Policy 169,176.

[228] J Lemiengre et al, 'Ethics policies on euthanasia in hospitals - A survey in Flanders (Belgium)' (2007)84 Health Policy 170,180.

[229] T Smets et al, 'Legal euthanasia in Belgium: characteristics of all reported euthanasia cases' (2009)47(12) Medical Care 1,3.

[230] ibid 3(Table 3).

an unwarranted constraint on 'patient autonomy'.[231] Such concerns may be unnecessary, however, as a study by Van den Block et al on end-of-life decisions from 2005 to 2006 found that euthanasia and other end-of-life practices are considerably more prevalent in inpatient palliative care units than in hospitals or care homes.[232] Contrary to the CFCE's views in its 2006/07 report, Van den Block et al concluded from their study that the Belgian Act promotes patient autonomy and allows patients to request euthanasia even when palliative care options are proposed and considered.

As noted in section 5.3.1, Bilsen et al's follow-up nationwide death certificate study on end-of-life medical practices in Flanders in 2007 found that in 1.8% of all deaths, lethal drugs were used without the patient's explicit request,[233] a rate that was lower than that in 1998 (3.2%) but slightly higher to that in 2001 (1.5%)[234]. These rates indicate that the Belgian Act has not completely deterred physicians from carrying out the unlawful practice of 'termination of life without request' or non-voluntary euthanasia[235]. Bilsen et al's study also found that 1.9% of all deaths were the result of euthanasia, a rate that was higher than that in 1998 (1.1%) and 2001 (0.3%). The rise shows that more patients are exercising their autonomy in expressing a voluntary request for euthanasia. The rate of 'intensified alleviation of pain and other symptoms at the end of life' had also increased from 18.4% of all deaths in 1998 and 22.0% in 2001 to 26.7% in 2007. On the one hand, this growth in palliative treatment in the form of symptom alleviation may show that more patients and physicians are exhausting palliative options before resorting to euthanasia. Alternatively, this growth may be due to an increased incidence of non-voluntary euthanasia under the guise of palliative treatment.

It is accepted that the law on euthanasia in Belgium focuses on patient autonomy. The emphasis placed on palliative care treatment by the PCA 2002, the MDB, and Caritas ensures that patients are informed of palliative care options before euthanasia is resorted to. This addresses the needs of patients who are likely to change their minds about their request for euthanasia once administered with adequate palliative care. However, as observed above, Belgian physicians have not yet fully abandoned the practice of

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[231] Lewis (n184) 136.

[232] L Van den Block et al, 'Euthanasia and Other End of Life Decisions and Care Provided in Final Three Months of Life: Nationwide Retrospective Study in Belgium' (2009)339 BMJ 2772.

[233] J Bilsen et al, 'Medical End-of-Life Practices under the Euthanasia Law in Belgium' (2009)361 N Engl J Med 1119.

[234] Bilsen et al's earlier study (n158), see section 5.3.1.

[235] 'Non-voluntary euthanasia' (text to ch1 n98).

‘termination of life without request’. Van den Block et al’s 2009 study found that such practice is also present in inpatient palliative care units.[236] The study found that 25 of 1,644 deaths had been the result of ‘termination of life without request’ (1.5%).

Bilsen et al’s 2004 study on end-of-life decisions found that ‘termination of life without request’ often occurred where communication with patients became impossible because of a sudden deterioration of the illness, or where communication on end-of-life decisions had been deferred for too long.[237] The findings in Bilsen et al’s study support an earlier observation made by van der Wal et al in 1993, prior to the Belgian Act.[238] Bilsen et al argue that such medical practice accords with the medical ethical principle of beneficence.[239] It is argued, however, that beneficence may be an excuse for medical paternalism,[240] as the incapacitated condition of the patients in such cases leaves them at the mercy of their physicians. As was noted by Faulder in 1985, ‘If beneficence is left entirely to the subjective judgment of [physicians] it…easily becomes an excuse for paternalism’.[241]

In a 2007 population-based survey, Chambaere et al found that ‘termination of life without request’ occurred more often in Flanders than in five other jurisdictions.[242] The results of the survey showed that in Flanders, out of 208 deaths by lethal medication (3.8% of all deaths), 66 (32%) were carried out in the absence of request or consent. Such ‘termination of life without request’ or non-voluntary euthanasia occurred mainly among patients who were 80 years of age or older, who were either in a coma, or suffering from dementia. Chambaere et al stated that such patients ‘fit the description of vulnerable patient groups at risk of life-ending without request’ and that ‘attention should therefore be paid to protecting these patient groups from such practices.’[243] In some cases, the physicians proceeded without consent because they felt that euthanasia was ‘clearly in the patient’s best interest’ and, in other cases, physicians felt that discussing euthanasia with the patient would have been harmful to them. The fact that

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[236] Van den Block (n232).

[237] J Bilsen et al, ‘The Incidence and Characteristics of End-of-Life Decisions by GPs in Belgium’ (2004)21 Family Practice 282,286.

[238] van der Wal (n155). See text to n155.

[239] See section 3.3.4.

[240] See section 3.3.8.

[241] Faulder (ch3 n160)158.

[242] K Chambaere et al, ‘Physician-Assisted Deaths under the Euthanasia Law in Belgium: A Population-Based Survey’ (2010) 182(9) Can Med Assoc J 895, 900. The five other jurisdictions were Denmark, Italy, the Netherlands, Sweden, and Switzerland.

[243] Chambaere (ibid) 899.

physicians have been more open to such a practice in Flanders,[244] suggests either a greater influence of the principle of beneficence, or a stronger culture of medical paternalism amongst Flemish physicians than elsewhere. Such paternalism may be due to physicians focusing on the quality of life of their patients.[245] Further multi-jurisdictional studies which include Belgium are considered in Chapter Six on 'the slippery slope argument'.[246] These also indicate a rate of non-voluntary euthanasia for Belgium which is higher than the Netherlands.

5.3.3 *Neonatal termination*

Despite neonatal termination being unlawful in Belgium, a survey on the 292 deaths of critically-ill infants between August 1999 and July 2000 found Belgian physicians to be carrying out neonatal termination in Flanders.[247] In 7% of cases, physicians administered a lethal dose of drugs, and in 16% of cases, drugs were administered to alleviate pain in doses that might also have shortened lifespan. Lethal doses were mainly administered to premature babies, who were less than a week old, with severe brain damage or severe congenital malformations or disabilities, and a poor quality of life. Approximately 68% of physicians who participated in the survey said that they would be willing to use lethal drugs to shorten the terminal suffering of a neonate, and 88% agreed that quality of life[248] should be taken into account in therapeutic decision-making made on behalf of neonates. The practice of non-voluntary euthanasia[249] in the form of neonatal termination demonstrates a culture of medical paternalism[250] in Belgium. Similar to the Netherlands, neonatal termination is practised based on a 'quality of life' judgement. However, there is no set criteria or guidelines to determine the quality of life of critically ill infants, in a manner like the Dutch *Groningen Protocol*.[251] Further, unlike in the Netherlands, neonatal termination has neither been approved by the Belgian medical profession, nor been officially excused by the Belgian public prosecution authorities.

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[244] J Cohen et al, 'Influence of Physicians' Life Stances on Attitudes To End-of-Life Decisions and Actual End-of-Life Decision-Making in Six Countries' (2008)34 J Medical Ethics 247.

[245] Cohen-Almagor (n154). See also text to n188.

[246] See section 6.7.

[247] V Provoost et al, 'Medical End-of-Life Decisions in Neonates and Infants in Flanders' (2005)365 Lancet 1315,1317(Table 2).

[248] See section 4.3.1.

[249] 'Non-voluntary euthanasia' (text to ch1 n98).

[250] See section 3.3.8.

[251] Cohen-Almagor (n176) 211.

5.3.4 *Summary for Belgium*

In conclusion, the law on euthanasia in Belgium is focused on patient autonomy. The Belgian Act had aimed to discourage the practice of 'termination of life without request' amongst Belgian physicians. Although the practice of non-voluntary euthanasia was found to have decreased from 3.2% in 1998 to 1.8% in 2007[252], this remains a concern as it shows that the laws are not followed absolutely and hence are liable to slippage, as discussed in Chapter Six. This practice may be due to a strong influence of medical paternalism amongst physicians who focus on the quality of life. As non-voluntary euthanasia occurred mainly among patients 80 years of age or older, who were either in a coma or suffering from dementia, such patients may be regarded vulnerable under the Belgian Act. Further evidence to demonstrate a culture of medical paternalism in Belgium is the fact that neonatal termination has been practised in Belgium based on a 'quality of life' judgement by physicians. As the Belgian Act covers the requests of emancipated minors and requests made in the advance directives of incompetent patients, such patients may also be vulnerable under the law. It is doubtful whether either of these requests are a reliable expression of a patient's autonomous wishes. Additionally, as the Belgian Act does not require a mental health evaluation, patients whose judgement may be impaired by depression or other mental disorders are not well protected. The Belgian Act has also been extended to those who merely anticipate a future coma, loss of independence, or progressive dementia. As discussed above, the competence of such patients is questionable.

A key strength of the Belgian law on euthanasia is its focus on palliative care. As the Belgian Act, the PCA 2002, the MDB, and Caritas emphasise the need for palliative care treatment, every Belgian hospital has a palliative care team and palliative home care is available nationally. The Belgian Act also includes control measures in the form of physician self-reporting, a review by the multi-disciplinary CFCE and appraisals by Parliament. However, the reporting rates for euthanasia have been low.

5.4 Switzerland

As noted in the earlier chapters, several British citizens have been accessing assisted suicide in more liberal jurisdictions like Switzerland. The Swiss right-to-die

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[252] See text to nn233-235.

organisation, Dignitas, has become the favoured destination for such ‘suicide tourists’ from England and Wales. For this reason, Switzerland will be examined in this section.

5.4.1 *Background*

Euthanasia is recognised as ‘homicide upon request’ or ‘voluntary euthanasia’[253] in Switzerland, and is a crime under the Swiss Penal Code (‘SPC’).[254] If an accused acted with honourable motives, however, an imprisonment sentence for euthanasia may be mitigated.[255] Sayid states that in some cases, the motives of the accused may be so benevolent that there may be a total exculpation for the crime.[256] Article 115 of the SPC only criminalises assistance in suicide that is motivated by selfish reasons.[257] It is submitted that the effect of Article 115 is similar to that of the DPP’s Policy in England and Wales. Under the DPP’s Policy, if an assisted suicide is compassionately motivated, and the suspect does not stand to personally gain from the victim’s death, then the suspect will most likely not be prosecuted.[258] As only the motivation of a person determines their culpability or innocence for the crime of assisted suicide, anyone may assist in suicides in Switzerland.[259] Thus, the SPC does not restrict the practice to Swiss physicians.

5.4.2 *Current law*

In Switzerland, a death as the result of an assisted suicide is regarded an ‘unnatural death’.[260] The police and coroner are informed of such deaths, and an inquiry is conducted.[261] If the inquiry finds that there was no selfish motive on the part of the person assisting the suicide, the death is officially recorded as a suicide and the case is

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[253] ‘Voluntary euthanasia’ (ch1 n7).

[254] *Strafgesetzbuch* [Penal Code] (‘SPC’) art 114 states, “[w]hoever kills another upon the latter’s earnest and urgent request is punishable by imprisonment”.

[255] SPC (n254) art 64.

[256] Sayid (ch1 n184) 553.

[257] SPC (n254) art 115 states that ‘[w]hoever from selfish motives, induces another to commit suicide or assists him therein’ is punishable.

[258] DPP’s Policy (ch1 n34) para43(6).

[259] When SPC (n254) art 115 was originally drafted in 1918, ‘the attitudes of the Swiss public were shaped by suicides motivated by honour and romance, which were considered to be valid motives. Motives related to health were not an important concern, and the involvement of a physician was not needed’: SA Hurst and A Mauron, ‘Assisted Suicide and Euthanasia in Switzerland: Allowing a Role for Non-Physicians’ (2003)326 BMJ 271,271.

[260] G Bosshard et al, ‘Open Regulation and Practice in Assisted Dying. How Switzerland Compares with the Netherlands and Oregon’ (2002)132 Swiss Medical Weekly 527,531.

[261] Ziegler and Bosshard (ch3 n108).

closed. Otherwise, the matter is referred to the public prosecutor.[262] A prosecution may be initiated if there is doubt regarding the patient's competence or ability to make an autonomous[263] decision to die.[264]

Today, non-profit right-to-die organisations such as Dignitas, Exit Association pour le Droit de Mourir dans la Dignité ('Exit ADMD'), and Exit Deutsche Schweiz ('EDS'), play a significant role in facilitating assisted suicides in Switzerland. Assisted suicides that take place at these right-to-die organisations are carried out according to the procedures which each of them have independently established. They each have their own internal protocols to determine whether patients meet their own required criteria for assisted suicide.[265] Exit ADMD assists only those who suffer from an incurable disease or who are terminally ill.[266] EDS requires a patient to be suffering from an 'incurable disease with unbearable pain',[267] and Dignitas requires the patient to be suffering from a 'disease that will inevitably lead to death or an unreasonable disability'[268]. Assistance with suicide by right-to-die organisations is usually given by non-medically trained volunteers.[269] It is argued that each of these sets of qualifying criteria are in effect based on a 'quality of life' judgement. When considering a request for assisted suicide, right-to-die organisations make quality of life judgements by assessing how poor or intolerable a person's physical condition is.[270]

As legally permitted assisted suicides in Switzerland are not restricted to Swiss residents, Dignitas offers its services to non-residents and foreign nationals who travel to Switzerland to obtain assistance in dying.[271] However, Exit ADMD and EDS limit their services to Swiss residents only. A well as providing suicide assistance to its members, Dignitas also operates as a counselling service to those who are

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[262] SJ Ziegler, 'Collaborated Death: An Exploration of the Swiss Model of Assisted Suicide for Its Potential to Enhance Oversight and Demedicalize the Dying Process' (2009) 37(2) J.L.Med.& Ethics 318, 323.

[263] See section 3.3.4.

[264] Hurst and Mauron (n259).

[265] Ziegler and Bosshard (ch3 n108).

[266] Griffiths (ch4 n152) 471.

[267] *Exit: Vereinigung für humanes Sterben Deutsche Schweiz* [Exit - German Swiss Association for Humane Death] <www.exit.ch> accessed 19 June 2014.

[268] Dignitas: to live with dignity - to die with dignity (site available in German, French, Italian and English) <www.dignitas.ch> accessed 19 June 2014.

[269] A Frei et al, 'Assisted Suicide as Conducted by a 'Right-to-Die'-society in Switzerland: A Descriptive Analysis of 43 Consecutive Cases' (2001)131 Swiss Medical Weekly 375,377.

[270] Dignitas, *How Dignitas Works: On what philosophical principles are the activities of this organisation based?* (June 2010) <www.dignitas.ch/images/stories/pdf/so-funktioniert-dignitas-e.pdf> accessed 19 June 2014.

[271] As noted by Dignitas, in one of its publications, a dignified death is a basic human right and 'no one should be discriminated against in any way, not even on the basis of where they live': *How Dignitas Works* (ibid).

contemplating suicide, and as an advocacy service for the recognition of similar patient rights in other countries.[272] Dignitas emphasises that their counselling service is aimed at preventing suicide, and that in so doing they are fulfilling the first half of their motto ‘To live with dignity - To die with dignity’.[273] In fact, Dignitas asserts a causal link between suicide legalisation and suicide prevention. In its evidence to the Commission on Assisted Dying, Dignitas stated that based on their 13 years of experience:

> paradoxically – the option of an assisted suicide without having to face the heavy risks inherent in commonly-known suicide attempts is one of the best methods of preventing suicide attempts and suicide ... Knowing about such an option will deter many from committing suicide through insufficient, undignified means.[274]

However, it is unknown whether this anecdotal experience is matched by a statistically significant reduction in Switzerland’s national suicide rates.

Almost all assisted suicides in Switzerland involve the self-administration of a lethal dose of barbiturates (taken by mouth) that has been prescribed by a patient’s family physician or by a physician affiliated with a right-to-die organisation.[275] However, a death certificate study by van der Heide et al found that 92% of all physician-assisted suicides in Switzerland between June 2001 and February 2002, involved physicians affiliated with a right-to-die organisation.[276] This is in contrast to the position in the Netherlands, where 70% of physicians who assist deaths are *huisartsen* or family-care physicians.[277] As noted by Bosshard et al, the role and responsibilities of physicians in assisted suicides offered through right-to-die organisations have not yet been legally defined in Switzerland.[278] It is argued that in situations involving physicians associated with right-to-die organisations, there is generally no opportunity for a physician to develop a meaningful relationship with a patient. This may result in a physician acting

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[272] S Luley, Dignitas, ‘A human life – what’s it worth?’, *Battle of Ideas - Satellite Debate* (Zürich, 8 October 2011) 2. Available on the Dignitas website. There is a constant effort by Dignitas to frequently update its website to clarify how it provides its services.

[273] ibid 2.

[274] Dignitas, *Call for Evidence by the Commission on Assisted Dying - Submission by ‘Dignitas – to live with dignity – to die with dignity’* (Forch, 2 May 2011) 8. Available on the Dignitas website.

[275] G Bosshard et al, ‘Assisted Suicide Bordering on Active Euthanasia’ (2002)117(2) Int J Legal Med 106,106.

[276] van der Heide (n158) 347.

[277] Refer to text to n73.

[278] Bosshard (n275) 107.

hastily, without giving adequate consideration to a patient's physical and mental health, their personal needs or medical history.[279]

Swiss law only permits physicians to prescribe barbiturates if it is 'accepted professional practice'.[280] Physicians who depart from the requirement of 'accepted professional practice' may lose their right to prescribe controlled substances, and may be potentially convicted of negligent homicide.[281] In 1999, a Swiss court held that physician-assisted suicide is accepted professional practice in cases where there are 'conditions indisputably leading to death'.[282] Nevertheless, up until 2008, there were still no prosecutions brought against physicians for prescribing lethal medication to individuals with non-fatal physical conditions.[283] As noted above, Dignitas will provide assistance to those with a disease that will inevitably lead to 'an unreasonable disability'. British citizens who have ended their lives at Dignitas have included those with non-fatal conditions like multiple sclerosis[284] and spinal cord injuries[285]. As noted in Chapter One, recent cases include an elderly arthritic British woman who ended her life to avoid 'prolonged dwindling', and a British man with progressive dementia.[286] It is submitted that this exemplifies a culture in which, provided there have been no selfish motives, Swiss prosecutors are reluctant to prosecute cases of assisted suicide that have been based on a competent request. In this respect, the law on assisted suicide in Switzerland is influenced by personal autonomy and self-determination[287]. As Lewy argues, right-to-die organisations prioritise 'patient autonomy' over the nature of a patient's underlying illness when facilitating the suicides of patients with various conditions.[288]

There is no requirement for a mental health evaluation under Swiss law. It is also not known whether patients who are suspected of lacking capacity are systematically

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[279] Quill (ch3 n201)162-63.

[280] G Bosshard, 'Switzerland' in Griffiths (ch4 n152) 471, 473.

[281] *Verwaltungsgericht des Kantons Zürich* [Administrative Court of the Canton of Zurich] VB.1999.00145, 15 July 1999 reported in ZBl 101/2000 489, AJP 2000 474. ('Zurich Case'); *Verwaltungsgericht des Kantons Aargau* [Administrative Court of the Canton of Aargau] BE.2003.00354, AGVE 2005 307, 28 January 2005 ('Aargau Case'). See also: Bosshard (n280) 473.

[282] Zurich Case (n281).

[283] Bosshard (n280) 475–6,478.

[284] See ch4 n7.

[285] Edwards (ch1 n21).

[286] See section 1.2.1.

[287] See section 3.3.2.

[288] Lewy (n183) 93, 101.

referred to a psychiatrist or psychologist for a mental health evaluation.[289] Thus, there is no safeguard to protect vulnerable patients[290] whose decisions may be impaired by depression or some other psychiatric or psychological disorder.

Since 1999, there have been Swiss cases where physicians have been prosecuted for the assisted suicides of individuals with mental disorders.[291] Whilst there may not have been any selfish motive on the part of the physicians involved in these cases, the patient's competence may nevertheless have been impaired. The patient would therefore not have been able to exercise patient autonomy when requesting assisted suicide. As noted by Bosshard, the main reason for such prosecutions is due to a perceived lack of due care by physicians to ensure the patient's competence and autonomy.[292]

Right-to-die organisations, in particular EDS, have volunteers trained in counselling to identify and refer depressed patients to a psychiatrist.[293] In a study of 748 assisted suicides in the Zurich canton between 1990 and 2000, of 331 suicides assisted by EDS, 2.7% were found to have depression or schizophrenia.[294] In a 2008 study, Bosshard et al found that right-to-die organisations will not provide suicide assistance where it is ascertained that depression affects an individual's capacity for decision-making.[295] Their study found that in 90 suicides assisted by EDS between 1997 and 2000, EDS volunteers found that 27% of patients had depression. It is contended that mental disorders which impinge upon competence may be going undetected by Swiss right-to-die organisations, as trained volunteers with no medical background and expertise are making decisions regarding the impact of depression on decisional capacity.[296] Thus, these right-to-die organisations may be facilitating the assisted suicides of vulnerable patients whose judgements are impaired by a mental disorder.

Not only is there no requirement for a mental health evaluation under Swiss law, a mental disorder can actually be the basis for a request for assisted suicide. In 2006, the

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[289] JB Wasserfallen et al, 'Assisted Suicide in An Acute care Hospital: 18 Months' Experience' (2008)138 Swiss Medical Weekly 239,240.

[290] See section 3.4.6.

[291] Zurich Case (n281); Aargau Case (n281).

[292] Bosshard (n280) 475–6, 478.

[293] Ziegler and Bosshard (ch3 n108) 296.

[294] G Bosshard et al, '748 cases of suicide assisted by a Swiss right-to-die organisation' (2003)133 Swiss Medical Weekly 310, 314.

[295] G Bosshard et al, 'Assessment of Requests for Assisted Suicide by a Swiss Right-To-Die Society' (2008)32 Death Studies 646,647,654-655.

[296] ibid 650.

Swiss Federal Supreme Court ruled that an incurable, permanent, serious mental disorder can be comparable to a serious physical condition.[297] The Court stated that in such cases, patients would be required to demonstrate that they have the required capacity to make a reasoned and settled decision to die, and that their decision is not the result of a treatable mental disorder. In a study of assisted suicides facilitated by EDS and Dignitas in the Zurich canton between 2001 and 2004, mental disorders accounted for 2% of EDS cases and 3.3% of Dignitas cases respectively.[298]

Just as voluntary euthanasia is recognised as a crime under Article 114 of the SPC, and is not practised by right-to-die organisations, the 2013 medical-ethical guidelines of the Swiss Academy for Medical Sciences ('SAMS'), which govern the medical profession in Switzerland, state that physicians must refuse any request for euthanasia when providing patients with end-of-life care.[299] The view of the SAMS in respect of euthanasia is similar to the views of the GMC and the BMA in England and Wales.[300] The SAMS guidelines further provide that, as Article 115 of the SPC applies to everyone, physicians are allowed to provide suicide assistance to patients approaching end-of-life. Under the SAMS guidelines, physician-assisted suicides are permitted if : i) the patient is at the terminal stage of a disease; ii) alternative treatment has been considered and perhaps even exhausted; iii) the patient is competent, and the persistent wish to end life has been well considered, without any external pressure. A third person, not necessarily a physician, has confirmed that the patient is competent and has made a voluntary autonomous request for death; and iv) the patient performs the act that leads to his or her death.[301] Additionally, the SAMS guidelines refer to palliative care.[302] They provide that patients in the final phase of life have a right to palliative care, which comprises medical treatment, nursing care, and psychological, social and spiritual support, with the aim of alleviating suffering and ensuring the best possible quality of life for the patient.[303] The medical limitations of palliative care are also acknowledged in

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[297] _ *v Gesundheitsdirektion des Kantons Zürich* [Unnamed complainant v Health Directorate of the Canton of Zurich], Bundesgericht (Tribunal fedéral, Tribunale federale) [Federal Supreme Court] 5P.481/2006, 19 February 2007.

[298] S Fischer et al, 'Suicide assisted by two Swiss right-to-die organisations' (2008)34 J Medical Ethics 810,812.

[299] *Schweizerische Akademie der Medizinischen Wissenschaften, Medizin-Ethische Richtlinien: Betreuung von Patientinnen und Patienten am Lebensende* [SAMS, Medical-ethical guidelines: end of life care] ('SAMS guidelines') (2013) para 4.2.

[300] See section 3.3.3.

[301] SAMS guidelines (n299) para4.

[302] See section 3.4.3.

[303] SAMS guidelines (n299) para3.1.

the guidelines. Thus, the SAMS guidelines accept the autonomous requests for physician-assisted suicide by terminally ill patients. The guidelines also focus on the need for palliative care to be exhausted first, before physician-assisted suicide is resorted to by patients and physicians. However, the SAMS guidelines do not mention the need for a mental health evaluation to ensure that patients have made competent autonomous decisions. In this regard, the guidelines have failed to include safeguards to protect vulnerable patients who may be depressed when requesting assisted suicide.

It was found in a 2008 study, that right-to-die organisations may not proceed with an assisted suicide if an alternative treatment is possible.[304] The study also found that right-to-die organisations exhaust palliative care as a medical option before resorting to assisted suicide. This suggests that Swiss right-to-die organisations may only assist in the suicides of those who have either already explored or exhausted palliative treatment options. It is, however, uncertain whether a patient's refusal of palliative treatment would rule out the provision of an assisted suicide.

Trained volunteers at right-to-die organisations not only mix the lethal medication, and remain with the patient whilst the latter ingests the drug, but they also manage any complications that arise during the procedure.[305] As noted earlier, complications such as difficulties in swallowing and the inability to ingest lethal substances are not uncommon in patients.[306] Additionally, non-medically trained volunteers may not be prepared or may not be trained to deal with situations where the patient remains in a coma for a lengthy period of time or vomits the medication. There have been instances, according to Ost, where the conduct of volunteers have gone beyond assistance and amounted to euthanasia.[307] For example, if volunteers hold up lethal medication to a patient's mouth for them to drink, it is difficult to determine whether this would qualify as 'self-ingestion' or 'self-administration'.[308] Bosshard notes a case in which two patients were in a coma several hours after they had taken the lethal drug and volunteers from a right-to-die organisation suffocated them with a plastic bag.[309] However, these claims were subsequently attributed to, and denied by, Dignitas. Dignitas assert that such

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[304] Wasserfallen (n289) 240.

[305] Ziegler and Bosshard (ch3 n108) 296.

[306] Bosshard (n275) 107.

[307] Ost (ch1 n122) 534-536.

[308] Ziegler (n262).

[309] Bosshard (n280) 475.

claims originate from their trial use of helium inhaled via a medical breathing mask, as an alternative to lethal medication:

> Media reports, politicians' assertions, and even the statement from a judgement of the administrative court of the canton of Zurich (!) which claimed that the persons wishing to end their lives had died with a plastic bag over their head are completely fictitious.[310]

Regardless of the truth, it is submitted that the present Swiss assisted suicide framework lacks proper guidelines and regulations. Assistance provided by volunteers may border on euthanasia, depending on the extent of the assistance.

As Switzerland has no centralised notification system for assisted suicide, there are no official statistics for assisted suicides. Thus, there is strong reliance on figures published by the right-to-die organisations themselves.[311] However, it is argued that although right-to-die organisations collect and maintain their own records of assisted suicide,[312] these records may not be complete. This is demonstrated in Imhof et al's 2011 study, which found that 61 out of 147 records of suicides assisted by EDS in the Zurich canton between 1990 and 2000 did not contain a medical report, and that the available medical reports in the other records contained varying amounts of detail.[313] However, without accurate medical reports there is no reliable way of knowing whether the medical conditions of patients would have indisputably led to death.[314] It is submitted that the lack of a formal record keeping requirement makes the current system open to abuse.

It is argued that, as physicians are required to ensure that the medical condition motivating a person's request for assisted suicide[315] is a 'condition indisputably leading to death', in cases where the request to die arises from existential suffering, physicians may be tempted to embellish other medical conditions of the patient in their medical reports to get them over this threshold.

Dignitas has made representations and formal submissions in the UK to interest groups, political parties, parliamentary committees, and the Commission on Assisted Dying.

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[310] *How Dignitas Works* (n270) 15.

[311] Bosshard (n260) 531.

[312] Bosshard (n294) 311.

[313] L Imhof et al, 'Content of Health Status Reports of People Seeking Assisted Suicide: A Qualitative Analysis' (2011)14 Medicine, Health Care, and Philosophy 265.

[314] Rothschild (ch2 n228) 72.

[315] ibid 72.

Dignitas has also submitted several *amicus curare* briefs in regard to end-of-life cases before the ECtHR. Dignitas asserts that as a non-profit organisation and advocacy group, its primary focus is on the right of a patient to a dignified life and death. Dignitas asserts that:

> people who inhabit a country should never be degraded by being considered the property of the state. They are the bearers of human dignity, and this is characterised most strongly when a person decides his or her own fate. It is therefore unacceptable for a state or its individual authorities or courts to choose the fate of its citizens.[316]

Dignitas' response to an enquiry from the Commission on Assisted Dying as to how they 'ensure that people are making a voluntary and considered choice and are not pressured into an assisted death' was to note that under Dignitas' procedures, 'the individual needs to take initiative again and again in order to proceed towards an [assisted suicide]'.[317] Dignitas also listed five specific safeguards which they have in place: (a) patients are each in contact with several different staff members of Dignitas, (b) patients are visited at home for a preliminary in-depth discussion, (c) one or more physicians who are independent of Dignitas assess the request, including at least two personal consultations, (d) at least two volunteers from Dignitas are present at the assisted suicide itself, each of whom are trained to assess the patient's decision and free will, and to look for possible influence by third parties, (e) relatives and friends of the patient are encouraged to participate, allowing a further opportunity to monitor the interaction between the patient and their loved ones.[318]

Whilst the Dignitas safeguards noted above serve to protect individual patients from the undue influence of others, it is less certain whether they address the concern expressed by some advocacy groups, that a law which permits assisted death will make some members of society feel generally that their lives are less valued.[319] In Switzerland, any such feeling would be one created by the SPC which only criminalises assisted suicides that are motivated by selfish reasons, rather than by the existence of right-to-die organisations such as Dignitas. Whilst Dignitas may have experienced some success

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[316] *How Dignitas Works* (n270) 27.

[317] Dignitas, *Commission on Assisted Dying – visit of 5 May 2011. Questions by the Commissioners according to the section 'International Visits' - A few notes for the Commissioners* (5 May 2011) 3. Available on the Dignitas website.

[318] ibid 3-4.

[319] See section 3.4.6.

with suicide prevention, groups in the UK which feel most threatened, such as the physically disabled, remain amongst the groups which Dignitas will assist to die.

5.4.3 *Summary for Switzerland*

In conclusion, there are several inconsistencies in the Swiss assisted suicide framework. Swiss law only allows physicians to prescribe lethal amounts of barbiturates for physical or mental conditions indisputably leading to death. Yet, right-to-die organisations, like Dignitas, do not restrict their services to those that are terminally or incurably ill. There have been no known prosecutions of physicians who have participated in the assisted suicides of patients with non-fatal conditions. This is despite the fact that the SAMS guidelines state that physician-assisted suicide should only be performed when the patient is terminally ill. The SAMS and right-to-die organisations both require palliative care to be exhausted first as a medical option, before assisted suicide is resorted to. As there is no legal requirement for a mental health evaluation, vulnerable patients whose decision-making capacity may be impaired, and they may not be protected under Swiss law. Further, as there is no national body to which assisted suicides are reported, there is no public accountability of the practice in Switzerland. This lack of formal regulation and transparency has resulted in differing practices for assisted suicides within Switzerland.[320] Under the Swiss framework, assistance provided by volunteers may also border on euthanasia, depending on the extent of the assistance.

5.5 Germany

This section will examine the law on assisted death in Germany. Whilst euthanasia is a crime in Germany, assisted suicide is not. German physicians are, however, not allowed to participate in assisted suicides. The following discussion will focus on the extent to which German physicians are allowed to make end-of-life medical decisions involving the terminally ill.

5.5.1 *Background*

For a long period of time, the term ‘euthanasia’ in Germany was predominantly used to describe Nazi atrocities committed during the Third Reich, when physically and

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[320] ibid 72.

mentally impaired people were murdered by the national socialist regime.[321] Today, euthanasia in Germany is recognised as ‘homicide upon request’ or ‘voluntary euthanasia’[322] under § 216 of the German Criminal Code (‘GCC’). A person who is charged for this offence is prosecuted for manslaughter rather than murder.[323]

5.5.2 *Current law*

As suicide is not a crime in Germany, assisted suicide is also not a crime provided the person committing suicide is capable of exercising control over their actions (‘*tatherrschaftsfdhig*’), and that they act out of their own free will (‘*freiverantwortliche Wille*’).[324] The person must not only be physically capable of ending their life, but must also have the required competence to exercise autonomy. Thus, the law on assisted suicide in Germany is based on self-determination[325] and personal autonomy.[326] Oduncu and Sahm observe that assisted suicide is only legally permitted in Germany in circumstances when the victim’s will to kill themselves is clearly documented and demonstrates sufficient independence from outside influences or pressures.[327] This is similar to the public interest factors in the DPP’s Policy in England and Wales requiring proof that the victim had made a voluntary, clear, settled and informed decision to commit suicide and that such a decision was free from any pressure.[328]

A physician’s participation in a patient’s death would violate the German code for professional medical conduct.[329] Thus, it is illegal for German physicians to administer lethal substances which cause death, even if this is the expressed will of the patient,[330] or

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[321] RT Maitra et al, ‘Do German General Practitioners Support Euthanasia? Results of a Nation-Wide Questionnaire Survey’ (2005)11 Eur J General Practice 94.

[322] ‘Voluntary euthanasia’ (ch1 n7).

[323] *Strafgesetzbuch* [Criminal Code] s 216 states: 1) If a person kills another after having been expressly and earnestly requested to do so by the person killed, the punishment shall be imprisonment for a term of not less than three years; 2) If extenuating circumstances are present, the punishment shall be imprisonment for a term of not less than six months.

[324] MP Battin, ‘Assisted suicide: Can we learn from Germany?’ (1992)22(2) Hastings Cent.Rep 44.

[325] See section 3.3.2.

[326] See section 3.3.4.

[327] FS Oduncu and S Sahm, ‘Doctor-Cared Dying instead of Physician-Assisted Suicide: A Perspective from Germany’ (2010)13(4) Medicine, Health Care, and Philosophy 371.

[328] DPP’s Policy (ch1 n34).

[329] J Schildmann et al, ‘Physician Assisted Suicide: Knowledge and Views of Fifth-Year Medical Students in Germany’ (2006)30 Death Studies 29.

[330] Bosshard (n9).

to cause a patient's death by not treating a medical condition.[331] Further, attempted suicide is regarded an 'accident' under § 323c of the GCC, and under § 221, a person is prohibited from abandoning another in a helpless situation if they have an obligation to provide assistance. Thus, German physicians not only have professional duty to save a patient's life, but also have a legal obligation to prevent the death of a suicidal patient.[332] Despite this legal situation, in a 2004 nationwide survey of the attitudes of German physicians towards euthanasia, 13% of respondents were found to have performed euthanasia at least once, whilst 38% had performed assisted suicide.[333] The study also found that the atrocities of the Third Reich played only a minor role in shaping the attitudes of German physicians towards euthanasia. This is consistent with an earlier study published in 1999, which also found that Nazi history only had a minor influence on the euthanasia debate in Germany.[334]

The German Association for Palliative Medicine ('DGP')[335] and the General Assembly of the Representatives of German Physicians[336] have both rejected any practices that hasten death, and regard them as being unethical.[337] The opposition by these professional medical bodies in Germany to practices that hasten death is a lot wider than the current opposition by the GMC and the BMA in England and Wales, to merely euthanasia and assisted suicide.[338] Nevertheless, Schildmann et al's 2009 survey on end-of-life medical practices by members of the DGP, found that 47 out of 692 cases involved non-participation of competent patients in end-of-life medical decisions, including two cases of non-voluntary euthanasia.[339] The reasons given by physicians for not consulting their patients were that decisions were made in the patients' best interests, and that there would have been more harm than benefit had patients been involved.[340] It is submitted

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[331] Oduncu and Sahm (n327). cf In England, physicians are permitted to withdraw or withhold life-sustaining treatment from patients.

[332] J Schildmann et al, 'End-of-Life Practices in Palliative Care: A Cross Sectional Survey of Physician Members of the German Society for Palliative Medicine' (2010)24 Palliative Medicine 820.

[333] Maitra (n321).

[334] RD Leichtentritt et al, 'Holocaust Survivors' Perspectives on the Euthanasia Debate' (1999) Soc Sci Med 185.

[335] *Deutsche Gesellschaft für Palliativmedizin* [German Association for Palliative Medicine].

[336] *Deutsche Ärztetag* [General Assembly of the Representatives of German Physicians].

[337] Oduncu and Sahm (n327).

[338] See section 3.3.3.

[339] Schildmann (n332) (Table 2). 'Non-voluntary euthanasia' is explained in text to ch1 n98.

[340] The reasons given by physicians in Schildmann's 2009 survey (n332) (Table 3) were similar to the reasons given by physicians in Chambaere's 2010 Belgian study (n242). In contrast to English law, decisions may only be made in the best interests of incompetent patients. Where patients are competent, patients have the absolute autonomous right to make their own medical decisions: discussed in section 2.3.2.

that such medical decisions suggest an influence of medical paternalism[341] amongst German physicians, which runs contrary to patient autonomy. Schildmann et al conclude in their study that this paternalistic approach may be largely due to there being no legislation on euthanasia and assisted suicide in Germany.[342]

As physicians in Germany are not legally permitted to provide suicide assistance, patients depend on the assistance of people who are not medically qualified, or on non-medical organisations to end their lives. One such organisation is the German Society for Humane Death (‘DGHS’),[343] which promotes suicide and assisted suicide as ways of achieving a painless and self-determined death.[344] The DGHS is an independent non-governmental organisation that provides information to those who are terminally ill, and wanting to end their lives. Its internal safeguards are, i) it only provides membership to those who have not received any medical or psychotherapeutic treatment for psychiatric illnesses or depression over the two years prior to membership, and ii) only members who have been with the DGHS for more than a year may request a copy of its booklet, *Dignified and Responsible Death*,[345] which contains a list of drugs and dosages necessary for a painless death. It is submitted that these safeguards are not sufficient to protect vulnerable patients. There is nothing to ensure that the services of the DGHS are restricted to the terminally ill, as is its stated focus. There should be a physician to make the relevant diagnosis and prognosis for terminal illness before an individual becomes a member. Not only does the DGHS not place any stress on palliative care,[346] but as there is no requirement for a mental health evaluation, vulnerable patients[347] who are depressed or experiencing any other mental disorder which impairs their decision-making capacity, are at risk. There is also the further possibility of a failed or ‘botched’ suicide as medications are ingested based on information provided by the DGHS with no proper supervision by healthcare professionals. Another organisation in Germany which provides suicide assistance is Dignitate Deutschland (‘Dignitate’) in Hannover. Dignitate is the German branch of the Swiss right-to-die organisation, Dignitas. Dignitate does not provide a patient with a lethal substance for assisted suicide, rather it facilitates suicide tourism to Switzerland

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[341] See section 3.3.8.

[342] Schildmann (n332).

[343] *Deutsche Gesellschaft für Humanes Sterben e.V.* [German Society for Humane Death].

[344] Battin (n324).

[345] DGHS, *Menschenwiirdiges und selbstverantortliches Sterben* [‘Dignified and Responsible Death’].

[346] See section 3.4.3.

[347] See section 3.4.6.

amongst German nationals. Nevertheless, non-medically trained people in Dignitate may not be able to detect depression or other mental disorders which affect the decisions of patients seeking assisted suicide in Dignitas. As noted in section 5.4, neither does Dignitas in Switzerland require a mental health evaluation.

German courts have placed some limits on the operation of non-medical organisations which provide suicide assistance. In 2008, an association called Dr. Roger Kusch Sterbehilfe e.V. helped Germans to commit suicide.[348] The only requirements were that an intention to end life has been documented, and that the patients had undergone a psychiatric evaluation. The association even assisted patients who were not in the last stages of terminal illness, and some who were not ill at all. In February 2009, the Hamburg Administrative Court prohibited the association from assisting in further suicides. Whilst the DGHS and Dignitate are non-profit organisations which merely provide information and referrals, this association was a commercial enterprise providing active assistance. The Court held that the commercial aid of suicide is a socially reprehensible act.[349]

There is on-going debate in Germany about the appropriate ethical and legal framework for end-of-life medical decisions.[350] Although the German Medical Association ('BÄK')[351] had initially rejected medical practices that hasten death,[352] since its 2011 guidelines were issued, it no longer considers assisted suicide to be against professional medical ethics. The BÄK's *Principles Concerning Terminal Medical Care* ('*PCTMC*') provide that:

> The duty of the physician is to preserve life, protect and restore health, relieve suffering and to be there for the dying until death, while respecting the patient's right of self-determination.[353]

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[348] Oduncu and Sahm (n327).

[349] *Kommerziell betriebene Suizidbegleitung als Gefahr für die öffentliche Sicherheit* [Commercially operated suicide accompaniment as a threat to public safety], Verwaltungsgericht Hamburg [Administrative Court of Hamburg] 8 E 3301/08, 6 February 2009.

[350] Schildmann (n332).

[351] *Bundesärztekammer* [German Medical Association].

[352] BÄK, *Bundesärztekammer Bekanntmachungen: Grundsätze der Bundesärztekammer zur ärztlichen Sterbebegleitung' (2004)95 Deutsches Ärzteblatt A2366* ['German Medical Association Notices: Principles of the German Medical Association Concerning Terminal Medical Care' (2004)95 German Medical Journal A2366].

[353] BÄK, *Grundsätze der Bundesärztekammer zur ärztlichen Sterbebegleitung (2011)103 Deutsches Ärzteblatt A346* ['Principles of the German Medical Association Concerning Terminal Medical Care' (2011)103 German Medical Journal A346] ('*PCTMC*') (18 February 2011).

The *PCTMC* not only focus on the sanctity of life,[354] but also promote self-determination. As observed by Oduncu and Sahm, the *PCTMC* give emphasis to palliative care and use the expression '*Sterbebegleitung*' which means 'accompanying the dying'.[355] They argue that physicians are not only obliged to provide basic care ('*basisversorgung*') to the terminally ill, but to also help them die with dignity.[356] This means that if a patient is terminally ill, the objective would be no longer to preserve life or to cure the illness, but instead to alleviate suffering.[357]

According to Oduncu and Sahm, the *PCTMC* permit life-sustaining treatment to be withheld or withdrawn from a terminally ill patient pursuant to their request. Such decisions are based on the principle of self-determination and an individual's right to personal autonomy. In 2007, Rittner observed that German physicians have been reluctant to withhold or withdraw life-sustaining treatment for fear that their conduct would be mistaken as the act that causes the patient's death.[358] In respect of terminally ill patients, Michalsen argues that the continuation of treatment is what would need to be justified, not its withdrawal. He observes that there has to be a clear indication that the life-sustaining treatment is likely to benefit the terminally ill patient,[359] and that the patient consents to such treatment, or at least that they would most likely consent if they could still make a decision.[360] Similarly, Fassier et al argue that a reluctance to withhold or withdraw life-sustaining treatment from the terminally ill who have requested its discontinuance can lead to a continuation of extraordinary measures, and the harmful overtreatment of patients.[361] This is in contrast to the law in England and Wales, where a competent person, whether terminally ill or not, has the absolute right to exercise their autonomy to refuse life-sustaining treatment. If a competent patient has refused life-sustaining treatment, English law prohibits physicians from treating them.[362]

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[354] See section 3.3.1.

[355] Oduncu and Sahm (n327).

[356] See section 3.4.4.

[357] Oduncu and Sahm (n327).

[358] C Rittner, '*Entscheidung am Lebensende ohne medizinische Unterstützung in Deutschland' (2007) 5(17) Rechtsmedizin 321* ['End-of-Life Decisions without Medical Assistance in Germany' (2007)5(17) Legal Medicine 321].

[359] This is similar to the approach in English law in respect of the withholding and withdrawing of life-sustaining treatment from incompetent patients, discussed in section 4.3.

[360] A Michalsen, 'Care for Dying Patients – German Legislation' (2007)33 Intensive Care Medicine 1823.

[361] T Fassier et al, 'Care at the End of Life in Critically Ill Patients: the European Perspective' (2005)11 Current Opinion in Critical Care 616.

[362] See section 2.3.2.

The *PCTMC* also recognise medical decisions with a ‘double effect’. Similar to the law in England and Wales,[363] the administration of excessive amounts of palliative medication requires a physician to merely intend relieving a patient of their pain and suffering, and not the shortening of life as a result.[364] However, Rittner notes that German physicians have been reluctant to prescribe or administer high dosages of palliative medication, once again, for fear that their conduct will be mistaken as the act that causes the patient’s death.[365] The *PCTMC* also state that life-sustaining treatment (including ANH) is mandatory for patients with a life-threatening illness that is not terminal. This principle applies equally to patients in a PVS. In the context of English law, this principle is in contrast to the House of Lords decision in *Bland*.[366] It is submitted that the BÄK is swayed by the ethical doctrine of ‘sanctity of life’ in cases involving non-fatal conditions, and that the patient’s ‘quality of life’ is not considered in such cases. The *PCTMC* also provide for cases of newborns with severe deformities with no prospect of improvement, extremely premature babies whose inevitable death is foreseeable, and newborns who have suffered extreme brain damage. The *PCTMC* allow life-sustaining treatment to be discontinued from such neonates with the consent of their parents. This is similar to the law in England and Wales,[367] where in cases involving critically ill or severely disabled neonates, end-of-life decisions are based on what is in the ‘best interests’ of a child, which is in effect a ‘quality of life’ judgement by physicians.

In cases concerning ‘advance decisions’, the BÄK has recognised advance directives (‘*betreuungsverfügungen*’) as an expression of a patient’s will since 1998.[368] On 17 March 2003, the German Federal Court of Justice (‘BGH’)[369] legally endorsed advance directives by holding that they are legally binding insofar as they relate to a particular medical treatment and the patient has not changed his or her mind.[370] Further legal endorsement was given to advance directives on 1 September 2009,[371] when the German Federal Parliament made advance directives on life-sustaining treatment, by

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[363] See sections 2.3.1 and 3.3.6.

[364] Michalsen (n360).

[365] Rittner (n358).

[366] Bland’s case (ch1 n12). See sections 2.3.3 and 4.3.3.

[367] See section 4.3.1.

[368] BÄK, *PCTMC* (n353).

[369] *Bundesgerichtshof* [Federal Court of Justice].

[370] *Bundesgerichtshof* [Federal Court of Justice] XII ZB 2/03, 17 March 2003.

[371] *Drittes Gesetz zur Änderung des Betreuungsrechts* [Third Amendment to the Guardianship Law] 29 July 2009, BGBl I, 2009, 2286.

patients who are dependent on such treatment due to an accident or a terminally illness, binding on physicians.[372]

On 25 June 2010, the BGH held that the withholding or withdrawal of life-sustaining treatment and medical decisions with a double effect are lawful so long as such actions reflect a patient's will or are carried out based on a patient's prior request.[373] The BGH overturned the conviction of a lawyer who had advised his client to remove her mother's feeding tube. The 71-year-old mother had been in a non-responsive coma for five years.[374] Shortly before her coma, she had insisted that she did not want to be kept alive artificially.[375] According to the German Minister of Justice, the BGH's decision was a major step toward respecting an individual's autonomous decision from the previous focus on 'sanctity of life', '[t]here can't be forced treatment against a person's will [as] [t]his is about the right of self-determination and therefore a question of a life in human dignity[376] until the end.'[377] The decision in this case reflects the current law on advance decisions on the withdrawal or withholding of life-sustaining treatment in England and Wales, though under English law, such advance directives would have to be in writing.[378] As established in Chapter Two, where previous known wishes or preferences are considered, this would amount to an extension of autonomy from the time when a patient was competent, to a time when they have become incompetent.

5.5.3 *Summary for Germany*

In conclusion, although euthanasia is illegal in Germany, and assisted suicide is allowed except by physicians, studies have demonstrated that German physicians have participated in not only euthanasia and assisted suicide, but non-voluntary euthanasia as well. Under the current law on assisted death in Germany, assisted suicides may not only have the potential for failure as they are not supervised by medical experts, but patients may also be vulnerable due to a mental disorder impairing their decision-

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[372] German Justice Minister Sabine Leutheusser-Schnarrenberger, quoted in J Baetz, 'Germany: Assisted suicide OK if patient consents' *The Guardian* (London,26 June 2010). cf. In English law on advance decisions, there is no restriction on the withdrawal or withholding of life-sustaining treatment to only cases of accidents or terminal illness (see section 2.3.3 under *Advance decisions*).

[373] *Bundesgerichtshof* [Federal Court of Justice] 2 StR 454/09, 25 June 2010.

[374] Baetz (n372).

[375] ibid.

[376] See section 3.4.4.

[377] Baetz (n372).

[378] See section 2.3.3 under *Advance decisions*.

making capacity, coercion or pressure. In Germany, medical decisions with a double effect and those involving the withholding and withdrawal of life-sustaining treatment are generally based on the principles of autonomy and self-determination for terminally ill patients. For conditions that are not terminal, Germany had been leaning in favour of the doctrine of sanctity of life. However, in the 2010 BGH case noted above,[379] the Court respected a non-terminally ill patient's previous autonomous decision and held that the decision to withdraw life-sustaining treatment from the patient was lawful.

5.6 Northern Territory, Australia

The Rights of the Terminally Ill Act ('ROTI Act') in the Northern Territory of Australia was the first statute in the world to legalise both assisted suicide and euthanasia by physicians.[380] After being in force for only nine months, the ROTI Act was overridden by the Australian Federal Parliament exercising its constitutional powers as described later in this section. Despite the ROTI Act's short lifespan, there are numerous lessons to be learnt from this legislation. The ROTI Act will be examined to identify parallel influences that affected its legalisation process, and to consider statutory provisions that could help inform law reform on assisted death in England and Wales.

Euthanasia and assisted suicide are both currently illegal in all States and Territories of Australia. However, on 25 May 1995, the Northern Territory Parliament ('NTP') passed the ROTI Act,[381] making euthanasia and assisted suicide by physicians legal in the Northern Territory.[382] The ROTI Act allowed physicians to prescribe and administer lethal substances to terminally ill patients who requested assistance to end their lives.[383] The Act was, however, only in force for nine months — from 1 July 1996 to 25 March 1997.[384]

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[379] 2 StR 454/09 (n373).

[380] AL Plattner, 'Australia's Northern Territory: The First Jurisdiction to Legislate Voluntary Euthanasia, and the First to Repeal It' (1997)1(3) DePaul J Health Care Law 645.

[381] Rights of the Terminally Ill Act 1995 (NT) ('ROTI Act').

[382] ibid sub-s 7(l)(a).

[383] Rights of the Terminally Ill Amendment Act 1996 (NT) ('ROTI Amendment Act').

[384] Plattner (n380).

5.6.1 *Background*

According to commentators, the influences which led the ROTI Act to be introduced into the NTP included an ageing community[385] that was becoming more interested in end-of-life options with increasingly secular values, and a strong belief in the right to choose; an increasing number of deaths from cancer and AIDS; limitations on the respite provided by palliative care;[386] and advances in sustaining human life[387] which were prolonging the dying process.[388] These influences overlap substantially with those currently shaping the debate on the legalisation of assisted death in England and Wales, as discussed in Chapter Three. When the Rights of the Terminally Ill Bill was introduced in the NTP, it was acknowledged that the right of terminally ill patients to decide when to end their lives was based on a respect for personal autonomy,[389] and that people who approach questions of life from different moral and religious perspectives should be allowed to live their lives in accordance with their values and beliefs so long as the practice of those values and beliefs does not adversely affect others.[390] It is accepted that this position is based on Mill’s principle of liberty.[391]

5.6.2 *The Rights of the Terminally Ill Act (ROTI Act)*

The ROTI Act provided that competent patients over 18 years, suffering from a terminal illness and experiencing pain, suffering or distress that is severe and to an unacceptable extent, could request that their physician assist them to terminate their life.[392] Terminal illness was defined as an injury or degeneration of mental or physical faculties which, in reasonable medical judgement will, in the normal course, without the application of extraordinary measures or of treatment unacceptable to the patient, result in the patient’s death.[393]

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[385] See section 3.2.3.

[386] See section 3.4.3.

[387] See section 3.4.2.

[388] P Quirk, ‘Euthanasia in the Commonwealth of Australia’ (1998)13 Issues L.&Med. 426.

[389] See section 3.3.4.

[390] Northern Territory, *Parliamentary Debates*, Legislative Assembly, 22 February 1995, 2495-2504 (Marshall Perron).

[391] Mill (ch3 n101) 9-10.

[392] ROTI Amendment Act (n383) s 4.

[393] ibid s 3.

The physician had to be satisfied that there was no medical treatment acceptable to the patient which could reasonably be undertaken to cure the patient, and that any medical treatment reasonably available was confined to palliative care.[394] Under the ROTI Act, two independent second opinions had to be obtained, one from a physician qualified in the patient's terminal illness, and the other from a psychiatrist. It is accepted that these were safeguards intended to confirm the medical diagnosis and prognosis, and the competence of the patient. Although an independent second opinion of the patient's terminally illness was required, the ROTI Act did not state what would happen if the physicians had differing opinions of a patient's prognosis. A 1998 study on seven cancer patients who applied for an assisted death under the ROTI Act found that it was difficult to make an accurate prognosis for cancer and that some patients had resorted to 'physician-shopping' to obtain the prognosis they desired.[395] In the case of one patient, an oncologist gave the patient's prognosis as nine months, but a dermatologist and a second oncologist assessed that she was not terminally ill.[396] The patient sought further second opinions until a physician diagnosed her as terminally ill with cancer.[397] Upon satisfying the requirements of the ROTI Act, the patient was given a lethal overdose. However, at the post-mortem she was found to be disease free.[398] This demonstrates that a prognosis of a terminal illness may be subject to differing second opinions, and that patients may resort to physician-shopping to get the diagnosis and prognosis they require to fulfil the legal requirements for an assisted death.

In respect of the independent second opinion required of a psychiatrist, the ROTI Act stipulated that a qualified psychiatrist had to be satisfied that the patient was of sound mind and not suffering from treatable clinical depression.[399] It is argued that the requirement for a qualified psychiatrist would adequately protect the vulnerable,[400] whose judgement or decision-making capacity may have been impaired due to a mental disorder. This would provide assurance that the patient is mentally competent and able

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[394] ibid s 7.

[395] DW Kissane et al, 'Seven Deaths in Darwin: Case Studies under the Rights of the Terminally Ill Act, Northern Territory, Australia' (1998)352 Lancet 1097, 1101.

[396] P Naughton, '"Peace at last" for Australian Euthanasia Woman', Reuters North American Wire (6 January 1997) <LEXIS, World Library, AllNews File>.

[397] DW Kissane, 'The Challenge of Informed Consent' (2000)19(6) J Pain Symptom Manage 473.

[398] Kissane (n395). No action was taken against the physicians who misdiagnosed the patient's condition, as physicians were immune to criminal or civil action, or professional disciplinary action, under the ROTI Amendment Act (n383) s 20, for anything done in good faith and without negligence.

[399] ROTI Amendment Act (n383) sub-s 7(1)(c).

[400] See section 3.4.6.

to make an autonomous request for assisted death. The 1998 study on the seven cancer patients noted above, found that the patients were not sure to what extent they could trust their psychiatrists with information that would allow the psychiatrists to understand their predicament.[401] With one patient, details about the death of her child and estrangement from another child were withheld during the psychiatric assessment. The researchers in the study argued that such experiences may have placed the patient in a lonely, grieving, demoralised position, and that associated depression may have gone unrecognised. The study concluded that if psychiatric assessments are seen as adversarial by patients, and viewed as obstructing successful treatment (including euthanasia or assisted suicide), rather than being a part of proper multidisciplinary care, patients will not be open during psychiatric assessments. Thus, mental health evaluations may not always be successfully carried out by psychiatrists, and the vulnerable may still be at risk.[402]

Although the social and ethical influences impacting on the drive for legislation in the Northern Territory were based on the right to autonomy and need for self-determination,[403] social judgements about the moral value of life were relevant to restrict the exercise of this right to a narrow context where a patient was terminally ill, not suffering from a treatable depression, and was suffering pain or distress at an unacceptable level.[404]

Under the ROTI Act, the attending physician had to be satisfied that the patient had reached their decision voluntarily, had considered the implications for their family, had been informed of the prognosis expected and understood the medical treatments reasonably available, including palliative care,[405] counselling and psychiatric support and extraordinary measures for keeping them alive.[406] This requirement would have helped ensure that a patient was competent and had made a voluntary, informed, well-considered and autonomous decision to end their life. It would have made certain that the patient had considered all the possible treatment options available, including palliative care. It also took into account the implications of an assisted death for the patient’s family. Although the ROTI Act required the patient to be informed of the

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[401] Kissane (n395).

[402] C Ryan et al, ‘Australian Psychiatry and Euthanasia’ (1996)4 Australasian Psychiatry 307.

[403] See section 3.3.2.

[404] Magnusson (ch2 n258) 1127.

[405] See section 3.4.3.

[406] ROTI Amendment Act (n383) sub-s 7(1)(e).

prognosis expected, as discussed in Chapter Two, an accurate prognosis in terms of 'life-expectancy' is often not possible for a terminal illness.[407] It is submitted that this may have been the reason why a prognosis in terms of life-expectancy was not included in the definition of 'terminal illness' in the ROTI Act.

Information on palliative care had to be provided by a physician with specialist qualifications in palliative care.[408] The attending physician was not to assist in a death if they believed there were palliative care options reasonably available to alleviate pain and suffering to levels acceptable to the patient.[409] It is argued that by involving a palliative care expert in the consultation process, the patient's specific needs in terms of pain, suffering and distress were more likely to be met. The attending physician was also prevented from providing any assistance to die if they believed there were palliative care options which could address the patient's concerns. This requirement emphasised the need to not only explore, but to exhaust palliative care options before resorting to assisted death. As such, it protected patients who were not aware of other treatment options, and helped assure that assisted death was an option of last resort.

A patient had to wait for at least seven days before signing a formal certificate of request to die, witnessed by their attending physician and a second physician.[410] It is accepted that the requirement for witnesses would have acted as a safeguard protecting vulnerable patients from undue influence, duress or coercion from third parties. If a further 48 hours had then elapsed from the signing of the certificate of request, and the patient had not withdrawn their request, the attending physician could then provide assistance.[411] It is argued that the 'seven-day' and '48-hour' periods were two 'cooling off' periods to allow a patient time to reconsider their decision and to discuss it with their family, loved ones, and perhaps even with their physician. As discussed in Chapter Three, the desire for death among vulnerable members in society who are terminally ill, is known to change.[412] A patient may have been depressed, feeling helpless, or feeling like they were a financial or emotional burden on their family when making the initial request. The cooling off periods would have given such vulnerable patients an opportunity to reassess their request. Additionally, the cooling off periods would have

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[407] 2004 HL Select Committee Report Vols I, II and III (ch1 n58). See section 2.4.2.

[408] ROTI Amendment Act (n383) sub-s 7(3).

[409] ibid sub-s 8(1).

[410] ibid sub-s 7(1)(i)-(k).

[411] ibid sub-s 7(1)(n)-(p).

[412] See section 3.4.6.

given a physician assurance of the certainty of the enduring character of their patient's request. However, there was no requirement for a patient to confirm their request at the time of assistance, even if they had received psychiatric treatment for clinical depression.[413] In this regard, the ROTI Act ignored the possibility that a patient may have changed their mind at the time of assistance. Thus, the 'cooling off' provisions in the ROTI Act may not have been effective as a safeguard. Nevertheless, it is accepted that there is a practical difficulty with requiring a patient to confirm their request at the time of assistance. If a patient's health has deteriorated from the time of the initial request, it may be difficult for them to confirm their request. A confirmation of request may have been excluded from the ROTI Act due to this practical difficulty.

The assistance which a physician was permitted to provide, included prescribing, or providing a lethal substance for self-administration, and administering the substance directly to the patient, provided the physician was not promised any reward or, subjected to any threats.[414] By including a qualification that the assistance was not to be influenced by any reward or threats, this provided assurance that there was no selfish gain, or personal motive, for the physician to assist the patient.[415] In the English context, this requirement is similar to the public interest factor in favour of prosecution in the DPP's Policy which focuses upon whether or not the suspect was motivated by the prospect of gain from the victim's death.[416] The medical records of patients who were assisted to die under the ROTI Act had to contain documentation of their oral and formal request, their state of mind at the time of signing the formal certificate of request, and the physician's belief that the request was made voluntarily and after due consideration.[417] It is submitted that as the medical records were not required to contain details about a patient's state of mind at any time after making their formal request, the patient's mental capacity and competence were disregarded at the time of assistance. Thus, the ROTI Act did not consider the possibility of a change in circumstances that could have led to either the patient becoming vulnerable, or the patient's desire for

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[413] TR Little, 'Comment, Protecting the Right to Live: International Comparison of Physician-Assisted Suicide Systems' (1997)7 Ind.Int'l & Comp.L.Rev. 435,442.

[414] ROTI Amendment Act (n383) s 3. The four patients who died under the ROTI Act used a computer-controlled injection mechanism provided by their physician, who in each case was present during the self-administration of the lethal medication: 'Third Euthanasia Death in Australia' *Agence France Presse* (Paris, 22 January 1997) <LEXIS, World Library, AllNews File>.

[415] This requirement is similar to the SPC (n254) art 115 (n257), which only criminalises assisted suicides that are motivated by selfish reasons. See section 5.4.

[416] DPP's Policy (ch1 n34) para43(6), see section 2.2.3 under *Suspect's motivation*.

[417] ROTI Amendment Act (n383) s 12.

death changing. As acknowledged above, this omission may have been deliberate due to potential practical difficulties. The medical records were also required to contain the attending physician's qualifications, the independent physicians' reports, information on the substance prescribed and any steps taken to perform euthanasia.[418] Such additional information helps control and monitor the actual practice of physician-assisted death, and ensures that only qualified experts participate in a patient's assisted death.

The ROTI Act provided immunity to physicians against criminal, civil, or professional disciplinary action for anything done in good faith and without negligence.[419] Such immunity was to address the reluctance which physicians might otherwise have had to assist their patients when a request for death was made. It is submitted that it is the fear of criminal prosecution, and of disciplinary action by professional bodies, that deters physicians from assisting their patients. This is clearly seen in the current law in England and Wales. As discussed in Chapter Two, the DPP's Policy specifically provides that if the suspect who assists in a victim's death is a medical doctor then this would be considered a public interest factor in favour of criminal prosecution.[420] As discussed in section 5.5, there is a similar fear among German physicians who are reluctant to withhold or withdraw life-sustaining treatment from terminally ill patients upon their request, and who are also reluctant to prescribe or administer high dosages of palliative medication to alleviate pain and suffering.

A copy of the death certificate and relevant sections of the medical record relating to the illness and death had to be forwarded to the Coroner.[421] The Coroner was required to provide annual advice to the Attorney-General on the number of patients who had been assisted to die under the ROTI Act.[422] The Attorney-General, in turn, was required to report to the Legislative Assembly of the NTP.[423] It is submitted that the reporting procedures would have amounted to safeguards to ensure that euthanasia and assisted suicide were medical practices that were properly controlled and regulated. These procedures not only permitted public oversight of the ROTI Act, but also provided assurance that there was no abuse of the law.

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[418] ibid s 12.

[419] ibid s 20.

[420] DPP's Policy (ch1 n34) para43(14).

[421] ROTI Amendment Act (n383) sub-s 14(1).

[422] ibid sub-s 14(2).

[423] ibid sub-s 14(2).

The ROTI Act was opposed by the Australian Medical Association, the Australian Association for Hospice and Palliative Care, mainstream religions, the Right to Life Association, and other organisations representing the aged and those with disabilities.[424] The Coalition Against Euthanasia[425] had also publicly challenged the ROTI Act, declaring that the assistance given by physicians was unethical.[426] As was noted in Chapters One and Three, there are similar objections currently being expressed to any proposed law which permits assisted death in England and Wales.[427] As a result of such fierce opposition and political lobbying, the Australian Federal Parliament overturned the ROTI Act by enacting the Euthanasia Laws Act, an overriding piece of federal legislation, which came into force on 25 March 1997.[428]

When the Euthanasia Laws Bill was presented to the Australian Parliament, several arguments were asserted, in favour of the Bill's objective of overriding the ROTI Act.[429] It was argued that patients had travelled to the Northern Territory from elsewhere in Australia to make use of the ROTI Act, thus making the ROTI Act a national issue. By contrast, (i) all other Australian States and Territories had consistently rejected the legalisation of euthanasia, thus indicating a clear national consensus against the ROTI Act, and hence (ii) the issue should not be driven by the Northern Territory legislature representing less than one percent of Australia's national population. It was further argued that (iii) the ROTI Act ran contrary to (a) 'the findings of every major committee of inquiry in the world' (with particular reference to the 1990 Remmelink Report,[430] and the 1994 House of Lords Select Committee on Medical Ethics[431]), (b) ethical principles of the medical profession, (c) the 'tenets' of every major religious group, (d) the concerns expressed by the Northern Territory's indigenous communities (which form approximately 23% of the Northern Territory's population),[432] and (e) 'the evidence of

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[424] MB Van Der Weyden, 'Deaths, Dying and the Euthanasia Debate in Australia' (1997)166(4) Med J Aust 173.

[425] The Coalition was composed of the Australian Medical Association, the Right to Life Association, and the Catholic, Anglican and Uniting churches: Rachel Bridge, 'Australia: Anti-euthanasia Lobby Plans Court Challenge' *South China Morning Post* (Hong Kong,7 January 1996).

[426] Bridge (ibid).

[427] See sections 1.3, 3.3.3, and 3.4.6 under *The disabled*.

[428] The Australian Federal Parliament can overrule the laws of its territories: Kissane (n395).

[429] First reading: Commonwealth of Australia, *Parliamentary Debates,* Legislative Assembly, 9 September 1996, 3672-3673 (Kevin Andrews). Second reading: Commonwealth of Australia, *Parliamentary Debates*, Legislative Assembly, 28 October 1996, 5905-5908 (Kevin Andrews).

[430] The Remmelink Survey (n85).

[431] *Report of the Select Committee on Medical Ethics* (ch3 n113).

[432] 1991 Australian Census, as cited by Senate Legal and Constitutional Legislation Committee, *Consideration of Legislation Referred to the Committee — Euthanasia Laws Bill 1996* (March 1997) 39.

widespread abuse of euthanasia in the Netherlands'.[433] Additionally, it was argued that (iv) the ROTI Act failed to provide 'a caring response for all dying people' due to its failure to address two outstanding issues in the Northern Territory — (a) relatively poor laws for the appointment of third parties to make medical decisions on behalf of a patient, and (b) inadequate standards of palliative care.[434]

Many of the arguments above are addressed elsewhere in this thesis. Concerns for vulnerable members of society based on the Remmelink Report and other suggested evidence of abuse in the Netherlands are considered in Chapter Six,[435] where no evidence is found to support them. The Report of the 1994 House of Lords Select Committee on Medical Ethics, professional medical ethics, religious viewpoints and the importance of adequate palliative care are all discussed in Chapter Three.

Contrary to the assertions of those who tabled the Euthanasia Laws Bill in the Australian Federal Parliament (as discussed above), when the Bill was debated and then assessed by a Senate Committee, some contention was expressed concerning (i) the true views of local indigenous communities on the ROTI Act,[436] and (ii) the true levels of public support throughout Australia for the ROTI Act.[437]

5.6.3 *Summary for the Northern Territory*

In conclusion, the ROTI Act was restricted to terminally ill adult patients. Although it included safeguards in the form of independent second opinions from a medical expert on the patient's terminal illness and a psychiatrist, patients had been able to resort to 'physician-shopping' to get the required diagnosis. Some patients had also not been fully cooperative during psychiatric evaluations, as such evaluations were thought to frustrate their chances of getting an assisted death. By requiring a physician to be satisfied that their patient had considered the implications of their decision, and had been informed of all the treatment options available, the ROTI Act had ensured that the patient's decision was a well-informed, well-considered autonomous decision. As physicians were prevented from providing any assistance if they believed there were palliative care options which could address a patient's concerns, assisted death was

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[433] First reading (Kevin Andrews) (n429) at 3672.

[434] ibid at 3673.

[435] See section 6.3.

[436] Senate Legal and Constitutional Legislation Committee (n432) 178-180.

[437] Commonwealth of Australia, *Parliamentary Debates*, Legislative Assembly, 28 October 1996, 5908-5911 (Christine Gallus), 5914-5917 (Nicholas Dondas), 5920-5923 (Anthony Albanese).

regarded an option of last resort under the ROTI Act. This provision also protected patients who were not aware of palliative treatment. The requirement for a patient to have signed the certificate of request in the presence of two witnesses would have protected vulnerable patients who may have been under pressure, duress or coercion at the time of request. The 'seven-day' and '48-hour' cooling off periods also gave vulnerable patients an opportunity to reassess their request, and gave physicians assurance of the certainty of their patient's request. However, as there was no requirement for a patient to confirm their request at the time of assistance, the ROTI Act had failed to protect patients who may have changed their mind, or felt pressured or compelled to proceed with, or follow through with their initial request. Additionally, as the ROTI Act provided immunity to physicians against legal action or professional disciplinary action, it addressed one of the main reasons for the reluctance of physicians to assist in assisted deaths.

5.7 Oregon, US

Traditionally, the law in the United States of America ('US') has regarded euthanasia and assisted suicide as crimes.[438] Further, the US Supreme Court ruled in 1997 that there is no constitutional right to assisted suicide.[439] However, this federal ruling does not prevent any US State from promulgating its own law regarding physician-assisted suicide.[440] Thus, the Death with Dignity Act ('DDA') in Oregon was narrowly voted into law in November 1994 by a citizen-initiated referendum.[441] It was the first successful attempt by a US State to legalise physician-assisted suicide.[442]

5.7.1 *Background*

The legalisation of physician-assisted suicide in Oregon was the result of a dissatisfaction with the medical profession and the development of a national 'right to die' movement.[443] Patients had become concerned about the distance between physicians

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[438] *Washington v. Glucksberg* 521 US 702 (1997), 710.

[439] ibid; *Vacco v Quill* 521 US 793 (1997).

[440] A Alvarez, 'The History of Suicide' in M Uhlmann (ed), *Last Rights: Assisted Suicide and Euthanasia Debated 63-65* (District of Columbia Ethics and Public Policy Center 1998), 614.

[441] Oregon Ballot Measure 16 (1994), also known as the Death with Dignity Act (Oregon) ('DDA').

[442] SR Martyn & HJ Bourguignon, 'Now is the Moment to Reflect: Two Years of Experience with Oregon's Physician-Assisted Suicide Law' (2000)8 The Eld LJ 1.

[443] T Purvis, 'Debating Death: Religion, Politics, and the Oregon Death with Dignity Act' (2012)85(2) Yale J Biology and Medicine 271.

and patients, the effect of modern medicine on patients, and the modern tendency for physicians to act simply as technicians and to lose sight of the patient as a person.[444] The legislation reflected a desire to regain autonomy,[445] and thus challenge the medical profession's authority.[446] Support for 'the right to die' was high in Oregon, according to Doyle, and nearly 60% of those Oregon citizens polled expressed support for legalising physician-assisted suicide for the terminally ill.[447] In 1994, a group known as Oregon Right to Die, along with other advocates of assisted death, proposed a ballot initiative in Oregon, i.e. Measure 16 or the DDA.[448] Hillyard and Dombrink observe that Oregon was a 'unique state both in terms of the long history of citizens using the "initiative" power as a tool of legal and social change and in terms of citizens' defiance toward both organised religion and outside political pressure'.[449]

Purvis observes that the Oregon Right to Die group promoted the DDA by appealing to Oregon citizens' individual self-determination,[450] desire for choice, and patient autonomy at the time of death. Some proponents, he notes, argued that patients had a right to choose the timing and manner of their deaths when faced with a terminal illness, rather than having to suffer an undignified,[451] possibly humiliating, and likely painful death.[452] He states that the DDA supporters described the legalisation of physician-assisted suicide as a right that upheld patients' choice, control, and freedom at the end of life. The DDA passed with 51% of the vote.[453] After a legal injunction and several court challenges,[454] the DDA finally became law on 27 October 1997.[455] Since the DDA provides that assistance under the DDA 'shall not, for any purpose, constitute suicide, assisted suicide, mercy killing or homicide, under the law', the cause of any death assisted under the DDA is officially attributed to the underlying illness.[456]

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[444] ibid.

[445] See section 3.3.4.

[446] D Hillyard, J Dombrink, *Dying Right: The Death With Dignity Movement* (Routledge 2001) 5-8, 15-18.

[447] B Doyle, 'Killing Yourself: Physician-Assisted Suicide in Oregon', in MO Steinfels (ed), *American Catholics, American Culture: Tradition & Resistance* (Sheed & Ward 2004) 25.

[448] Purvis (n443). Oregon was the first US state to implement the citizen's 'initiative' process, which enabled petitions signed by a minimum number of Oregon voters to force a public vote or persuade lawmakers: ibid.

[449] Hillyard, Dombrink (n446) 70.

[450] See section 3.3.2.

[451] See section 3.4.4.

[452] Purvis (n443).

[453] ibid.

[454] *Lee v. Oregon* 107 F 3d 1382 (9th Cir 1997), 1386.

[455] Or Rev Stat §§ 127.800-127.897 (1998).

[456] ibid § 127.880.

5.7.2 *The Death with Dignity Act (DDA)*

The DDA permits physicians to prescribe lethal drugs to terminally ill adult (18 years and above) residents of Oregon.[457] The DDA places the following requirements on the patient and the attending physician. The patient must i) be capable,[458] ii) have a terminal disease, and iii) have made one written and two oral requests to die.[459] The attending physician is required to i) confirm the above conditions together with a consulting physician,[460] ii) refer the patient for counselling if the attending or consulting physician believes that the patient's judgement is impaired by depression or some other psychiatric or psychological disorder,[461] and iii) inform the patient of all feasible alternatives, such as comfort care, hospice care, and pain-control options.[462]

As a means of policing physician-assisted suicide in Oregon, the DDA requires physicians to file reports each time they write a prescription for lethal medication.[463] Besides the written prescriptions, physicians have to report all deaths that result from the prescribed medication to the Oregon Public Health Division ('OPHD') of the Oregon Health Authority ('OHA').[464] The reports include a copy of the patient's written request, the physician's compliance form, and a psychiatrist's compliance form if a mental health evaluation was carried out.[465] It is submitted that there is no mechanism to enforce the reporting requirements, and neither are there any penalties imposed on physicians who choose to disregard these requirements.[466] As such, the self-reporting procedure has been criticised due to the possibility of physicians 'under-reporting'. This was acknowledged by the OPHD in its first annual report in 1999, where it stated that '[it is] difficult, if not impossible, to detect accurately and comment on underreporting'.[467] It added that 'the reporting requirements can only ensure that the

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[457] ibid § 127.800.

[458] 'Capable' is defined as 'able to make and communicate decisions about their health care'. ibid § 127.800.

[459] ibid § 127.850.

[460] ibid §§ 127.800, 127.815, 127.820.

[461] ibid § 127.825.

[462] ibid § 127.815.

[463] ibid § 127.855.

[464] Before an organisational restructure in 2009, the OPHD was known as the Oregon State Health Division ('OSHD') and was within the Oregon Department of Human Services ('ODHS'): ibid § 127.865.

[465] Oregon Administrative Rules rr 333-009-0000 to 333-009-0030 (OHA, Public Health Division: Reporting requirements of the Oregon DDA).

[466] H Hendin et al, 'Physician-Assisted Suicide: Reflections on Oregon's First Case' (1998)14(3) Issues L.&Med 243.

[467] OPHD, *Oregon's Death with Dignity Act: The First Year's Experience* (First Annual Report).

process for obtaining lethal medications complies with the law'.[468] In its 2006 annual report, the OPHD stated that it merely monitors the DDA, and does not intend to 'ferret out' abuse.[469] It only investigates cases in which physicians' reports have deficiencies or do not correlate with the death certificates or other information, and it reports cases involving inadequate reporting or unexpected side effects to the Oregon Board of Medical Examiners or the Board of Pharmacy respectively.[470]

An annual statistical report of the OPHD data is made available to the public.[471] These annual OPHD reports include incidence data, and data on demographics, underlying illness, end-of-life care and concerns, complications and timing, and data about the process of dying after the lethal medication has been ingested.[472] It is accepted that the information in the annual reports allows for transparency and public oversight of the DDA. Nevertheless, physicians are not required to report the numbers of requested prescriptions that are refused and reasons for such refusal.[473] This affects the transparency of the physicians' decision-making process.[474] As Hendin and Foley observe, the OPHD 'does not collect the information it would need to effectively monitor the law'.[475]

Terminal illness is defined by the DDA as 'an incurable and irreversible disease that has been medically confirmed and will, within reasonable medical judgement, produce death within six months'.[476] However, as discussed in Chapter Two,[477] studies show that reliably measuring life expectancy in this context is very difficult. Physicians in Oregon have similarly expressed doubts about their ability to determine whether an individual has less than six months to live.[478] In 1996, Lee et al found that over 50% of Oregon physicians were not confident they could make such an accurate prediction on life

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[468] ibid.

[469] OPHD, *Eighth Annual Report on Oregon's Death with Dignity Act* 1, 9, 12-13.

[470] ibid 13.

[471] Or Rev Stat § 127.865 (1998).

[472] DDA Annual Reports available at 'Death with Dignity Act Annual Reports' (OHA) <http://public.health.oregon.gov/providerpartnerresources/evaluationresearch/deathwithdignityact/pages/ar-index.aspx> accessed 19 June 2014.

[473] R Lunge et al, *Oregon's Death with Dignity Law and euthanasia in the Netherlands: factual disputes* (Report commissioned by the Vermont Legislative Council, 2004).

[474] WE Hiscox, 'Physician-Assisted Suicide in Oregon: The "Death with Dignity" Data' (2007)8 Med.L.Int'l 197.

[475] H Hendin & K Foley, 'Physician-Assisted Suicide in Oregon: A Medical Perspective' (2008)24 Issues L.&Med. 121,121-122.

[476] Or Rev Stat § 127.800 (1998).

[477] See section 2.4.2 (text to ch2 nn381-386).

[478] Ganzini (ch3 n246) 2367.

expectancy.[479] The OPHD annual reports demonstrate this limitation. The reports indicate that patients who have opted not to use their prescription have lived longer than six months.[480] For example, the 2000 OPHD annual report showed a patient having received a lethal prescription more than eight months before ingesting it.[481] The 2004 OPHD annual report had a patient die in 2003, after having obtained a lethal prescription in 2001.[482] The fact that physicians have been inaccurate in their estimation of their patients' prognoses is evidence that it is difficult to assess the terminal phase.[483] This concern was also considered by the House of Lords' Select Committee in its report on the ADTI Bill 2004 ('2004 HL Select Committee Report').[484] Nevertheless, it is submitted that the DDA has taken account of the limitations of physicians when estimating life expectancy. This is because it specifies that the disease should, 'within reasonable medical judgement' produce death within six months. As noted in the recommendations of the 2004 HL Select Committee Report, '[this] reflect[s] the realities of clinical practice as regards accurate prognosis'.[485]

In Oregon, if a patient is refused a prescription by one physician, then they might yet be able to obtain a prescription from a more 'accommodating' physician ('physician-shopping').[486] An example of a case of 'physician-shopping' under the DDA is the 1999 case of Kate Cheney, an 85-year-old terminally ill patient, who had been denied by three physicians before finally receiving a lethal prescription.[487] This case is discussed in detail in Chapter Six,[488] in relation to possible 'slippery slope' concerns. According to the 2001 OPHD annual report, over the first three years of the DDA's operation, only 41% of patients received their prescription from the first physician asked, whilst the

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[479] M Lee et al, 'Legalising Assisted Suicide – Views of Physicians in Oregon' (1996)334 N Engl J Med 310,312.

[480] MP Battin et al, 'Legal Physician-Assisted Dying in Oregon and the Netherlands: evidence concerning the impact on patients in "vulnerable" groups' (2007)33(10) J Medical Ethics 591,594.

[481] OPHD, *Oregon's Death with Dignity Act: The Second Year's Experience* (Second Annual Report) 12.

[482] OPHD, *Sixth Annual Report on Oregon's Death with Dignity Act* 4.

[483] Glare, Christakis (ch1 n64).

[484] 2004 HL Select Committee Report Vols I, II and III (ch1 n58).

[485] 2004 HL Select Committee Report Vol I (ch1 n49) para 269(c)(iii).

[486] Martyn & Bourguignon (n442) 13. The phenomena of 'physician-shopping' had also occurred under the ROTI Act, where patients looked for physicians who provided the required diagnosis for a terminal illness. Refer to text of n395.

[487] EH Barnett, 'A Family Struggle: Is Mom Capable of Choosing to Die?' *The Oregonian* (Portland,17 October 1999).

[488] See section 6.5.

remaining 59% requested a lethal prescription from more than one physician before finding a 'willing' participant to the DDA.[489]

Additionally, suicide advocacy groups such as Compassion and Choices have a practice of referring patients to physicians who are known to be 'willing'.[490] This is demonstrated in the 1999 case of Helen.[491] Helen was an 86-year-old terminally ill patient, whose physician refused to assist in her suicide. A second physician also refused, on the grounds that Helen was depressed. Helen's husband then contacted Compassion and Choices, who referred her to a willing physician who gave her a favourable medical assessment.[492] This case, too, is discussed in Chapter Six,[493] in relation to 'slippery slope' concerns. In 2002, Hamilton noted that at least 86% of the reported assisted suicide cases in Oregon between 1998 and 2002 were handled by suicide advocacy groups.[494] In 2008, Hendin and Foley observed that a physician affiliated with a suicide advocacy group provided the consultation in 58 of 61 (95.1%) consecutive cases of patients receiving physician-assisted suicide in Oregon.[495] It is submitted that the extent to which suicide advocacy groups in Oregon are involved in the practice of physician-assisted suicide raises concerns about the objectivity of the process and the safety of vulnerable patients.[496] As suicide advocacy groups may be facilitators of the DDA, there would be a strong influence of bias on the part of physicians affiliated with such groups.[497]

There is no requirement under the DDA for the consulting physician to act independently of the primary physician. As such, the consultation requirement could be satisfied by a friend or colleague of the primary physician, who would be more likely to share the same opinion as the latter than if they were wholly independent.[498] It is argued that the element of 'independence' is essential to ensure that the consulting physician is able to freely and objectively assess the patient, and to challenge the attending

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[489] OPHD, *Oregon's Death with Dignity Act: Three years of legalized physician-assisted suicide* (Third Annual Report) 19(Table 3).

[490] Hiscox (n474).

[491] K Foley and H Hendin, 'The Oregon Experiment' in K Foley and H Hendin (eds), *The Case Against Assisted Suicide: For the Right to End-of-Life Care* (Johns Hopkins University Press 2002).

[492] P Reagan, 'Helen', (1999)353 Lancet 1265.

[493] See section 6.5.

[494] NG Hamilton, 'Oregon's Culture of Silence' in Foley and Hendin (n491).

[495] Hendin & Foley (n475).

[496] J Pereira, 'Legalizing euthanasia or assisted suicide: the illusion of safeguards and controls' (2011)18(2) Current Oncology e38,e39. See section 3.4.6 on 'protecting the vulnerable'.

[497] ibid e39.

[498] As observed with the Dutch experience, prior to the Dutch Act, consultant physicians ended up being facilitators rather than independent evaluators. Refer to text to nn66-67.

physician's decision-making where necessary.[499] There is also nothing in the DDA to prevent an attending physician from 'shopping around' until they find a consulting physician who is prepared to give a supportive confirmation of the patient's request and condition.[500] Thus, the requirement for a consulting physician to confirm the attending physician's diagnosis and prognosis may not amount to an effective safeguard under the DDA.

As evidence consistently links the desire to end one's life to depression,[501] physicians are required to refer a patient to a psychiatrist or psychologist if they suspect a mental disorder or depression causing impaired judgement.[502] However, the OPHD annual reports indicate a downward trend in the percentage of patients being referred for formal psychiatric or psychological evaluation, from a high of 37% in 1999,[503] to only 1.4% in 2011[504] and 2.6% in 2012.[505] Of the 673 total reported deaths between 1998 and 2012, only 42 patients (6.2%) had been referred for a psychiatric or psychological evaluation.[506] In 2010, only one of the 65 patients who died by lethal prescription had been referred.[507] In 2011, there was only one referral out of the 71 deaths,[508] and in 2012, only two referrals out of the 77 deaths.[509] In an interview, Ganzini stated:

> I think it's risky how low the rate of mental health evaluation is because people with depressive disorders are more likely to be able to get a (lethal) prescription if you're not…careful. [Patients who want to end their lives often suffer from a treatable depression,] and a trial of depression treatment should be the first approach, not a lethal prescription.[510]

It is submitted that physicians in Oregon are generally not competent to assess the mental state of a patient. Physicians providing a lethal prescription are less likely to

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[499] Hendin (n466) 250.

[500] FG Miller et al, 'Can Physician Assisted Suicide be Regulated Effectively?' (1996)24 J.L.Med.& Ethics 225,226.

[501] See section 3.4.6 under *The depressed*.

[502] Or Rev Stat § 127.800 (1998).

[503] OPHD, Second Annual Report (n481) 12(Table 4).

[504] OPHD, *Oregon's Death with Dignity Act — 2011* (14th Annual Report).

[505] OPHD, 15th Annual Report (ch3 n242) 2.

[506] ibid.

[507] OPHD, *Oregon's Death with Dignity Act — 2010* (13th Annual Report).

[508] OPHD, 14th Annual Report (n504).

[509] OPHD, 15th Annual Report (ch3 n242).

[510] T Christie, 'Assisted-Suicide Law Passes 10-Year Mark' *The Register-Guard* (Eugene,19 March 2008) cited in Patients Rights Council, 'Special Report: 10 Years Under Oregon's Assisted-Suicide Law', (2008)22(2) The Update.

know the patient well due to the occurrence of 'physician-shopping'. The OPHD annual reports show that the median length of the physician-patient relationship between the request and the death by lethal prescription between 1998 and 2012, was 12 weeks, though the median length for 2012 alone was somewhat higher, at 19 weeks.[511] Additionally, the attending and consulting physicians may not have the adequate knowledge, expertise or experience to reliably diagnose depression, let alone whether such depression is causing an impaired judgement.[512] As Battin observes, in the absence of a standardised depression-screening tool, there is a risk that a physician will fail to recognise depression when it occurs. It is not sufficient to merely rely on the professional competencies of physicians when screening for depression.[513]

It is argued that even with a mental health evaluation, the DDA may fail to protect some patients whose request for a lethal prescription is influenced by depression. Ganzini et al's 2008 study of a sample of patients (18) who had been prescribed with lethal drugs showed that one in six of them (3) had been suffering from undiagnosed clinical depression, although all of them were evaluated by a mental health professional.[514] As concluded by the researchers in their study, the DDA 'may not adequately protect all mentally ill patients'.[515] Chochinov et al contend that psychiatrists need to have an existing relationship with a patient before making successful assessments about their competency.[516] This is demonstrated in an earlier 1996 study by Ganzini et al of attitudes of Oregon psychiatrists.[517] They found in their study that only 6% of Oregon psychiatrists and psychologists were confident that in the absence of a long-term relationship with a patient, they could satisfactorily determine in a single visit whether that patient was legally competent to commit suicide. The majority were more confident, however, about assessing decision-making capacity over an extended period of time.

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[511] OPHD, 15th Annual Report (ch3 n242).

[512] K Foley and H Hendin, 'The Oregon Report: Don't Ask, Don't Tell' (1999)29(3) Hastings Cent.Rep 37,39.

[513] MP Battin, 'Physician-Assisted Dying and the Slippery Slope: The Challenge of Empirical Evidence' (2009)45 Willamette L.Rev. 91,124,125.

[514] L Ganzini et al, 'Prevalence of Depression and Anxiety in Patients Requesting Physicians' Aid in Dying: Cross Sectional Survey' (2008)337 BMJ a1682.

[515] ibid.

[516] Chochinov (ch1 n79).

[517] L Ganzini et al, 'Attitudes of Oregon Psychiatrists toward Physician-Assisted Suicide' (1996)153 Am J Psychiatry 1469.

A psychiatric evaluation under the DDA is also likely to fail as a safeguard to protect vulnerable patients due to the possibility of 'shopping around' for an 'accommodating' psychiatrist who will provide the desired mental health evaluation. Besides the case of Helen, discussed earlier,[518] this is illustrated by the case of Kate Cheney (also considered earlier).[519] A psychiatrist found Kate to have had mild, potentially reversible mental depression.[520] Kate consulted two other mental health professionals who found her decision-making capacity to be intact.[521] She also obtained a competency evaluation from a clinical psychologist, who concluded that there was no severe impairment that would limit her ability to make a medical decision.[522] Battin argues that the differences in mental health evaluations may have been because Kate's impairment was temporary, and therefore different clinicians were seeing her in different conditions. Nevertheless, it is uncertain how differing mental health assessments are to be reconciled when they occur.[523]

Studies from Oregon show that most patients receiving a prescription under the DDA were enrolled in hospice care, and that the legalisation of physician-assisted suicide has resulted in more hospice referrals and more training by physicians in palliative care.[524] The 2012 OPHD annual report shows that between 1998 and 2012, 586 (90.4%) of the 673 individuals who received assistance to die had been enrolled in hospice care.[525] In 2011, 59 (96.7%) of the 71 patients who ingested lethal medication were enrolled in hospice care,[526] whilst in 2012, 64 (97%) out of 77 patients were enrolled.[527] Most of these patients were enrolled in hospice care either at the time the prescription was written, or at the time of death. This demonstrates that the majority of patients in Oregon sought physician-assisted suicide as an adjunct to palliative care, rather than as an alternative to palliative care. Palliative care is also promoted by suicide advocacy groups, like Compassion and Choices. Campbell and Cox note in their 2010 research

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[518] See text to nn491-492.

[519] D Reinhard, 'In the Dark Shadows of Measure 16', *The Oregonian* (Portland, 31 October 1999). For the case of Kate Cheney, see text to n487.

[520] Foley and Hendin (n491) 156.

[521] L Ganzini, 'Letter to the Editor, Physician-Assisted Suicide' (2006)163(6) Am Journal Psychiatry 1109.

[522] Barnett (n487) 5, 7.

[523] Battin (n513) 126.

[524] TE Quill, 'Legal Regulation of Physician-Assisted Death — The Latest Report Cards' (2007)356 N Engl J Med 1911. See section 3.4.3 on 'palliative care'.

[525] OPHD, 15th Annual Report (ch3 n242).

[526] OPHD, 14th Annual Report (n504).

[527] OPHD, 15th Annual Report (ch3 n242).

paper on the collaboration between hospice and physician-assisted death, that Compassion and Choices ‘makes referrals to hospice a primary feature of its patient care counselling’ to ensure that physician-assisted death is practiced responsibly.[528]

The DDA requires a patient to make their request for assistance twice orally and once in writing.[529] As a safeguard protecting vulnerable patients, there are two ‘cooling off’ periods before a prescription is issued. There must be a 15-day lapse between the patient’s initial oral request and the writing of a prescription, and a 48-hour lapse between the patient’s written request and the writing of the prescription.[530] The ‘cooling-off’ periods ensure that the patient’s request is voluntary, informed and well-considered. To ensure that the patient’s desire for death remains unchanged, and is not the result of pressure, the DDA requires that immediately before a prescription is written, the attending physician verifies that the patient is making an informed decision.[531] A further safeguard protecting vulnerable patients is that a patient’s written request must be witnessed by at least two people who can verify that the patient is competent, and that the decision is voluntary and informed. At least one witness must not be a relative, the patient’s beneficiary, or an owner or employee of the treating healthcare facility.[532] The attending physician is also prohibited from acting as a witness.[533] This increases the assurance that the patient’s request is voluntary and that they are not being coerced or influenced by third parties.[534]

Under the DDA, patients are able to collect their drugs weeks or months before they actually ingest them. The 2012 OPHD annual report shows that between 1998 and 2012, the mean interval between first request and death by ingestion was 46 days.[535] However, this mean figure lies within a range of 15 to 1,009 days, and some of those receiving lethal drugs do not even take them until longer periods of time have elapsed. Thus, the DDA does not have any safeguards to ensure that when the patient subsequently takes the lethal drugs, they are capable, acting voluntarily and not suffering from any mental

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[528] CS Campbell and JC Cox, ‘Hospice and Physician-Assisted Death: Collaboration, Compliance, and Complicity’ (2010)40(5) Hastings Cent.Rep 26,26–7.

[529] Or Rev Stat § 127.840 (1998).

[530] ibid § 127.850.

[531] ibid § 127.830.

[532] ibid § 127.810.

[533] ibid § 127.810.

[534] Little (n413) 442.

[535] OPHD, 15th Annual Report (ch3 n242).

disorder, and are not taking the drugs under duress or undue influence.[536] There is no way of knowing whether the conditions that existed at the time when the drugs were prescribed, continue to exist when the drugs are taken.[537] Further, there are no safeguards in the DDA to ensure that the lethal medication is stored safely, or returned to the pharmacy if unused. There is also no account taken of the unused drug, should the patient then die naturally. As argued by Gianelli, physicians should witness patients' deaths to guard against any misuse of the lethal medications.[538] However, there is no requirement in the DDA for physicians to be present when the drugs are taken.

The 2012 OPHD annual report indicates that between 2001 and 2012, the prescribing physician was present at the time the lethal medication was ingested in only 26% of cases (108 out of 416 deaths),[539] and at the time of death (after the lethal medication was ingested) in only 16% of cases (96 out of 591 deaths). It is submitted that complications that arise when ingesting the lethal medication, or cases where patients regain consciousness after ingesting the lethal medication, are likely to go unaddressed under the DDA. Such cases have been highlighted in the 2012 OPHD report which shows that 22 (4.4%) out of 496 individuals who died from the lethal prescriptions since 1998 experienced complications in the form of regurgitation, and a total of six patients regained consciousness after ingesting the prescribed lethal medications.[540]

It is submitted that the DDA does not effectively prevent assistance from being provided during the self-ingestion. Although the DDA refers to a 'patient's act of ingesting medication',[541] it does not specify the exact means of taking the medication. The DDA also does not require the physician to determine that the patient is capable of self-administering the lethal drugs. As observed by Jeffrey and Teahan, this raises questions about the degree of assistance which may lawfully be provided to the patient.[542] This is illustrated in a 1999 case in Oregon, involving the assisted suicide of a 43-year-old man whose relative held a drink mixed with the prescribed lethal medication so that the man was able to drink from a straw.[543] In this case, the assistance

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[536] Keown (n24) 172.

[537] Baroness Finlay and Lord Carlile, *A Question of Public Safety* (ch2 n400).

[538] DM Gianelli, 'Dutch Euthanasia Expert Critical of Oregon Approach' *American Medical News* (American Medical Association, Chicago,15 September 1997).

[539] OPHD, 15th Annual Report (ch3 n242) 5(Table 1).

[540] ibid.

[541] Or Rev Stat § 127.875 (1998).

[542] D Jeffrey and M Teahan, Living and Dying Well, *What's happening in Oregon?* (2010).

[543] EH Barnett, 'Coos County Drops Assisted-Suicide Inquiry' *The Oregonian* (Portland,17 March 1999).

was regarded as a legal act.[544] However, in the absence of clear guidelines, such conduct could have been held to constitute euthanasia.

Tolle et al argue that most patients who initially consider obtaining lethal medication, do not persist with their request.[545] This is demonstrated in their 2004 study on the characteristics of dying Oregonians, which found that while 17% of dying Oregonians consider the option of assisted death, approximately only one out of 1,000 actually obtain a lethal dose of medication.[546] This argument is also supported by the 2012 OPHD annual report which indicates that since the DDA was passed in 1997, 64% of patients (673 out of 1,050 lethal prescriptions) had died from ingesting those medications, whilst the remainder had either died from natural causes or had a status that was as yet unknown.[547] Ganzini and Dahl note that the prescription is described as an 'insurance policy' by sufferers of progressive, incurable conditions who believe that the end of their lives will be more tolerable by knowing that they have the ability to end it, should it become intolerable.[548] Similarly, Savage observes that for many who obtain a prescription, it is enough to have the comfort of knowing that they have the means to end their lives, even if they never choose to do so.[549]

Of the 77 deaths under the DDA during 2012, most (67.5%) were aged 65 years or older, with the median age being 69 years.[550] This was similar to the previous year. Of the 71 deaths during 2011, most (69.0%) were also aged 65 years or older, with the median age being 70 years.[551] Of the 65 deaths during 2010, most (70.8%) were over age 65 years, with the median age being 72 years.[552] It is concluded that the law on physician-assisted suicide in Oregon is mainly utilised by its elderly population (defined as those aged 65 years or older). In the English context, one of the main social influences for law reform on assisted death is the growing aging population.[553] As in

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[544] EH Barnett, 'Laws Separate Euthanasia and Assisted Suicide' *The Oregonian* (Portland,14 April 1999).

[545] SW Tolle and PB Bascom, 'Responding to requests for physician-assisted suicide' (2002)288 JAMA 91.

[546] SW Tolle et al, 'Characteristics and Proportion of Dying Oregonians Who Personally Consider Physician-Assisted Suicide' (2004)15 J Clinical Ethics 111.

[547] OPHD, 15th Annual Report (ch3 n242).

[548] L Ganzini and E Dahl, 'Physician-assisted suicide in Oregon' in D Birnbacher and E Dahl (eds), *Giving Death a Helping Hand: physician-assisted suicide and public policy, an international perspective* (Springer 2008). See also: section 3.3.4 under *Respect for autonomy*.

[549] L Savage, 'Facing a Terminal Illness - Should how, and when you die, be your last right?' (2010)12 New Critic.

[550] OPHD, 15th Annual Report (ch3 n242).

[551] OPHD, 14th Annual Report (n504).

[552] OPHD, 13th Annual Report (n507).

[553] See section 3.2.3.

previous years, the 2012 OPHD report found that the most frequently mentioned end-of-life concerns by those who utilised the DDA were loss of autonomy (93.5%),[554] a decreasing ability to participate in activities that made life enjoyable (92.2%), a loss of dignity (77.9%),[555] and being a burden[556] on family, friends or caregivers (57.1%).[557] 35.1% of patients requested physician-assisted suicide because they feared losing control of their bodily functions. As discussed in Chapter Three, similar concerns have been raised by those in favour of legalising assisted death in England and Wales.

In 2007, there were 49 deaths under the DDA. This corresponds to 15.6 deaths under the DDA per 10,000 total deaths in Oregon.[558] In 2008, there were 60 deaths (19.4 per 10,000 deaths),[559] in 2009, there were 59 deaths (19.3 per 10,000 deaths),[560] in 2010, there were 65 deaths (20.9 per 10,000 deaths),[561] in 2011, there were 71 deaths (22.5 per 10,000 deaths),[562] and in 2012, there were 77 deaths (23.5 per 10,000 deaths).[563] It is concluded that although there is a low rate of assisted deaths pursuant to the DDA, there has been a marginal increase in the number of such deaths. Nevertheless, despite the concerns over safeguards in the DDA noted above, there have been no 'record highs' of deaths under the DDA in Oregon.[564]

5.7.3 *Summary for Oregon*

In conclusion, safeguards – such as the 'cooling off' periods and the requirement for witnesses to be present when a patient makes their written request – provide assurance that patients are competent, and are making a voluntary request for assisted suicide. As discussed, the majority of patients in Oregon seek physician-assisted suicide as an adjunct to palliative care, rather than as an alternative. Nevertheless, the safeguards in the DDA may not be effective to protect vulnerable patients in Oregon. There is the possibility of 'under-reporting' to the OPHD, as there is no legal mechanism to enforce

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[554] See section 3.3.4.

[555] See section 3.4.4.

[556] See section 3.4.6 under *Patients as a burden on others*.

[557] OPHD, 15th Annual Report (ch3 n242).

[558] OPHD, *Oregon's Death with Dignity Act — 2007* (10th Annual Report).

[559] OPHD, *2008 Summary of Oregon's Death with Dignity Act* (11th Annual Report).

[560] OPHD, *2009 Summary of Oregon's Death with Dignity Act* (12th Annual Report).

[561] OPHD, 13th Annual Report (n507).

[562] OPHD, 14th Annual Report (n504).

[563] OPHD, 15th Annual Report (ch3 n242).

[564] Patients Rights Council, 'Special Report: 10 Years Under Oregon's Assisted-Suicide Law' (n510).

the reporting requirement. The DDA requires the patient to be terminally ill and to have a life expectancy of less than six months. However, studies have demonstrated that it is difficult to make such an accurate terminal prognosis. There is also the potential for ‘physician-shopping’ under the DDA. Patients are not only able to seek prescriptions from more ‘accommodating’ physicians, but attending physicians may also be able to look for more supportive consulting physicians and psychiatrists. The involvement of suicide advocacy groups also challenges the objectivity of the practice of physician-assisted suicide in Oregon. A further issue with the law is that with the low referral rate for a psychiatric or psychological evaluation, physicians may fail to recognise depression or other mental disorders that cause impaired judgement in patients. Even with a mental health evaluation, studies in Oregon have shown that this still fails to protect some patients suffering from depression. As patients are able to collect their lethal medication weeks or months before they take them, and physicians are not required to be present when the medication is taken, there is no guarantee that the conditions which existed at the time the prescription was written continue to exist when the medication is eventually taken. Complications that arise when ingesting the lethal medication or after the ingestion are also unlikely to be addressed, as is the possibility of active assistance being provided by others during the self-ingestion. As observed above, physician-assisted suicide in Oregon is mainly resorted to by its elderly population, 65 years or older.

5.8 Conclusion

The legal developments concerning assisted death in the jurisdictions discussed in this chapter, can inform the reform agenda for the legalisation of physician-assisted suicide in England and Wales by providing the following valuable reference points and lessons.

As the first valuable reference point, it was shown that in four of the jurisdictions discussed – the Netherlands, Belgium, the Northern Territory (Australia), and Oregon (US) – there has been specific legislation on physician-assisted death in some form. The exemption from legal or disciplinary action provided by these laws addressed the reluctance of physicians to assist in their patients’ deaths. By contrast, in the other two jurisdictions considered – Switzerland and Germany – existing practices stem from their respective Penal Codes and professional guidelines, and have been relatively unregulated.

Secondly, the chapter demonstrated a varying emphasis on personal autonomy between the jurisdictions. Although the Dutch Act is based upon a patient's 'unbearable suffering' which cannot be improved, the patient may refuse palliative care. Thus, the Dutch Act focuses on absolute personal autonomy. However, the Belgian Act does not respect absolute patient autonomy, as it requires a physician to confirm a diagnosis of 'incurable disorder'. The ROTI Act and DDA, by contrast, both require the patient to be terminally ill. Under the ROTI Act, the patient must also be suffering to an unacceptable and severe extent.

Thirdly, the chapter noted varying control measures between the jurisdictions to regulate the practice of assisted death. Control measures are included in the Dutch Act and the Belgian Act in the form of reporting procedures for physicians, checks by multi-disciplinary review committees, and an assessment and appraisal by Parliament. Similarly, as a means of policing physician-assisted death in Oregon and the Northern Territory, physicians are required to file reports each time they write a prescription for lethal medication. By contrast, in Switzerland, no such reporting requirements exist for either right-to-die organisations or physicians.

Fourthly, although Swiss courts only allow physician-assisted suicide for conditions indisputably leading to death, physicians associated with right-to-die organisations have been prescribing lethal medication for patients with non-fatal conditions as well.

Fifthly, the chapter demonstrated that, as is the case in England and Wales, physicians in Germany are not permitted to provide suicide assistance. Thus, patients depend on the assistance of people who are not medically qualified to end their lives. This may expose vulnerable patients to the risk of mental disorders going undetected, complications arising during the dying process which go unaided, and failed suicides due to inappropriate medication.

Sixthly, the chapter found that in the Northern Territory of Australia, the ROTI Act was intended to address the concerns of an aging population, who were aware of the limitations of palliative care, and were concerned with advances in medical technology which merely 'prolonged death'. These influences overlap substantially with those currently shaping the debate on the legalisation of assisted death in England and Wales. In Oregon, by comparison, the drive for more patient autonomy was a key influence.

In addition to these reference points, several lessons were noted. Firstly, the chapter found that vulnerable patients, whose judgement is impaired by depression or other mental disorders, are at risk under the Dutch Act, the Belgian Act, and the DDA, as none of these require a mandatory mental health evaluation. Similarly, mental disorders which impinge upon competence may also go undetected at right-to-die organisations in Switzerland. Even when such referrals occur, studies in Oregon have demonstrated that psychiatrists and psychologists are not confident, in the absence of a long-term relationship with a patient, that they could satisfactorily determine in a single visit whether the patient was competent to make a decision to end their life. The chapter further found through the limited experience with the ROTI Act that if psychiatric assessments are seen as adversarial by patients, and viewed as merely frustrating one's request for death, then patients may not be fully open and honest during psychiatric assessments. Those psychiatrists and psychologists with long-term patient relationships, are perhaps more likely to earn patient trust, or detect the withholding of relevant information.

As a second lesson, the effectiveness of legislation in the Netherlands, Belgium, Oregon, and the Northern Territory relies heavily on physician self-reporting, whose reports may be biased so as to better fit the requirements of the law. However, by making an annual statistical report of data available to the public, this allows for transparency and public oversight.

A third lesson has been the significance of palliative care. A key strength of the Belgian law on euthanasia, is its focus on palliative care. Not only does the Belgian Act require physicians to discuss palliative treatment options with their patients, but the PCA 2002 also requires every patient approaching the end-of-life to experience palliative care. The Belgian Act, the PCA 2002, and Caritas all emphasise the need for palliative care treatment. The extensive availability of palliative care in Belgium, addresses the needs of the many patients making end-of-life decisions, whose needs can be met by adequate palliative care. This emphasises that euthanasia is to be an option of last resort. The chapter also found that most patients receiving a lethal prescription under the DDA in Oregon had received some form of palliative care, despite no legal requirement to do so. The legalisation of physician-assisted suicide has resulted in more hospice referrals and more training by physicians in palliative care. This provides a strong indication that by permitting assisted death, concerns that palliative care will be displaced as the option of first resort are unfounded. Under the ROTI Act, information on palliative care had to be provided by a palliative care expert, and there could be no assisted death if the attending physician believed there were palliative care options reasonably available.

Fourthly, the various safeguards intended to confirm the medical diagnosis and prognosis, and competence of the patient were noted. In the Northern Territory and Oregon, two independent second opinions from a physician qualified in the patient’s terminal illness, and a psychiatrist had to be obtained. The chapter also found that the ROTI Act and the DDA had similar safeguards in their requirements for witnesses and cooling off periods. Under both laws, patients are required to have signed a written request for death in the presence of two witnesses. This would protect vulnerable patients who have been subjected to pressure from family members. The two cooling off periods in both Acts give patients an opportunity to reassess their request, and assures physicians of the genuineness of the patient’s request for death. Under the DDA, the physician also has to verify that a patient is making an informed decision immediately before the prescription is issued.

A concern with the DDA that is highlighted in the chapter is that as there is no emphasis on the ‘independence’ of consulting physicians. As a result, such physicians may end up being facilitators of the DDA rather than independent evaluators. This concern is addressed in the Netherlands and Belgium, where the SCEN and LEIF networks provide suitably trained physicians to act as independent consulting physicians under each of their laws.

The chapter found that as the DDA allows patients to collect their medication weeks or months before they actually take them, there is no way of knowing whether a patient’s personal circumstances have remained the same or have changed at the time when the medication is taken. Other concerns with the DDA are that complications that arise when the lethal medication is taken, or cases where patients regain consciousness after taking the medication, are not expressly provided for. Neither does the DDA safeguard against assistance being provided during the ingestion, as it does not specify the exact means of taking the medication. These concerns are similar to those highlighted in Switzerland, in regard to the involvement of non-medically trained volunteers. These issues are however addressed in the Netherlands. Under the Dutch Act, a physician is required to either stay with the patient continuously or be immediately available until the patient dies. This not only addresses any complications during and immediately after an assisted death, but also avoids misuse of the lethal medication supplied for assisted suicide, or other abuse of the law.

Fifthly, the chapter also demonstrated that the phenomenon of ‘physician-shopping’ in Oregon has caused a negative impact on the DDA. Due to ‘physician-shopping’, physicians or psychiatrists in Oregon are less likely to be able to diagnose depression, or any other mental disorder in their patients. Such ‘shopping’ was also noted to have occurred under the ROTI Act. The chapter also noted that as suicide advocacy groups may be facilitators of the DDA, the involvement of physicians affiliated with suicide advocacy groups may further undermine the DDA safeguards.

Sixthly, although the initial intent of legislation in the Netherlands, Belgium and Oregon, was to limit assisted death as a medical option to a particular group of people, experiences from these jurisdictions indicate that the laws have been extended to a wider group of people than was originally intended. The extension of the Dutch law on assisted death to patients suffering from the early onset of dementia, to incompetent patients through their advance declarations, to medical conditions such as dementia (including Alzheimer’s disease), and to minors between the ages of 12 and 16 years may support concerns of a ‘slippery slope’ in the Netherlands. The extension of the Dutch law from voluntary euthanasia[565] to non-voluntary euthanasia[566] for newborns may also support ‘slippery slope’ concerns. In Belgium, extending the scope of ‘mental suffering’ to those who merely anticipate a future coma, loss of independence, or progressive dementia may also provide support for ‘slippery slope’ concerns. By extending the law to a wider group of patients, the laws on assisted death in both the Netherlands and Belgium may have failed to adequately protect such vulnerable members of society. The acceptance of these extensions to the law indicate a change in societal values after the legalisation of assisted death.[567] The extent to which the assisted death laws in the Netherlands, Belgium and Oregon support such concerns of a ‘slippery slope’ is discussed in the following chapter.

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[565] ‘Voluntary euthanasia’ (ch1 n7).

[566] ‘Non-voluntary euthanasia’ (text to ch1 n98).

[567] Pereira (n496) e39.

Chapter 6: The Slippery Slope Argument

6.1 Introduction

This chapter will critically examine the ‘slippery slope’ argument, which is a form of argument often raised by those opposed to the legalisation of assisted death in England and Wales. As slippery slope arguments are not unique to the UK, the chapter will evaluate the slippery slope argument against the experience of three of the six foreign jurisdictions considered in Chapter Five – the Netherlands, Belgium and Oregon. These are the jurisdictions whose assisted death practices are governed by current legislation. As Switzerland and Germany do not have legislation governing assisted death,[1] the slippery slope argument will not be investigated in these jurisdictions. The Northern Territory of Australia will also not be investigated, as assisted death was only briefly made legal by legislation in this jurisdiction.

Before considering the extent to which experiences in the Netherlands, Belgium, and Oregon support the slippery slope argument, the chapter will review the definition of a slippery slope argument, and the forms of this argument most commonly asserted in relation to assisted death. Common slippery slope ‘mechanisms’ will also be described.

The chapter will consider whether evidence from the Netherlands, Belgium and Oregon bears out the presence of a slippery slope, or whether, on the contrary, it demonstrates that euthanasia and assisted suicide can be controlled and regulated effectively without adverse effects on the vulnerable.[2]

The chapter will demonstrate that the expansion of circumstances for lawful euthanasia in the Netherlands provides some support for concerns of a slippery slope. In Belgium, slippery slope concerns are also supported by both an expansion of circumstances held to be lawful and a disregard for the current regulations by both the physicians and enforcement authorities. In Oregon, whilst no evidence of actual slippage is found, several risk factors are identified which constitute potential slippery slope ‘mechanisms’.

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[1] ‘Assisted death’, defined in section 1.1.

[2] See section 3.4.6.

The chapter will also examine whether there is evidence to support a slippery slope argument that a law on voluntary euthanasia[3] will lead to a stronger likelihood of non-voluntary euthanasia[4] taking place. This argument will primarily be evaluated in relation to the Netherlands, as this is the only jurisdiction that has substantial data both before and after the Dutch Act came into force. A similar evaluation of Belgium is not possible, as there is no data on the rates of voluntary and non-voluntary euthanasia for the period prior to the Belgian Act. Multi-jurisdictional studies are also reviewed to determine whether they also indicate a slippage from voluntary to non-voluntary euthanasia.

As noted in the section which follows, slippery slope concerns can potentially arise in any area of the law. On this basis, the chapter will also consider whether the current English law concerning the withdrawal and withholding of life-sustaining treatment provides support for slippery slope concerns.

6.2 Definition of 'slippery slope'

As Lode observes, slippery slope arguments generally take the following form: 'We should resist some practice or policy [at the top of the slope] on the grounds that allowing it could lead us to allow some other practice or policy that is clearly objectionable [at the bottom of the slope]'.[5] Between top and bottom may be many little steps, or 'slippages', and the slope is described as being 'slippery' because no matter where one decides to draw the line between the top and the bottom, it is impossible to hold it.[6] A step on to the top of the slope will on this view lead inexorably toward the bottom.[7]

Slippery slope arguments are not limited to assisted death. They have been asserted across varied subjects including the regulation of abortion, freedom of speech, tobacco, torture, and government surveillance.[8] In relation to assisted death, slippery slope

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[3] 'Voluntary euthanasia' (ch1 n7).

[4] 'Non-voluntary euthanasia' (text to ch1 n98).

[5] E Lode, 'Slippery Slope Arguments and Legal Reasoning' (1999)87(6) Calif.L.Rev 1469,1471.

[6] F Schauer, 'Slippery Slopes' (1985) 99(2) Harv.L.Rev. 361,378.

[7] DA Jones, 'Is There a Logical Slippery Slope from Voluntary to Non-voluntary Euthanasia?' (2011)21(4) Kennedy Institute of Ethics Journal 379,380.

[8] E Volokh, 'The Mechanisms of the Slippery Slope' (2003) 116 Harv L Rev 1026.

arguments have been key to the campaigns of anti-euthanasia activist groups. For example, Care Not Killing argue on their website as follows:

> If assisted suicide or euthanasia is legalised any ‘safeguards’ against abuse, such as limiting it to certain categories of people, will not work. Instead, once any so-called ‘right-to-die’ is established we will see incremental extension with activists applying pressure to expand the categories of people who qualify for it.[9]

Similarly, Not Dead Yet assert on their website that:

> Proponents claim they seek a small change in the law. But this is a crack that can be steadily opened wider and wider until any person may assist another disabled person to die without consequence.[10]

Slippery slope concerns also featured prominently in the submissions received by the House of Lords’ Select Committee on the ADTI Bill 2004, as noted in its report.[11]

Not all those who raise concerns of a slippery slope in relation to assisted death pose the same arguments; neither do they all articulate their arguments in detail. Some merely express a general concern. Whilst not all anti-euthanasia activist groups have expressed their arguments in detail, the variations of the slippery slope argument most commonly discussed by academic commentators have been the ‘logical’ argument and the ‘empirical’ argument. These are outlined in the following two sections.

6.2.1 *The logical slippery slope argument*

The logical form of the slippery slope argument (the ‘logical’ argument) is described by Rachels as follows:

> Once a certain practice is accepted, from a logical point of view we are committed to accepting certain other practices as well, since there are no good reasons for not going on to accept the additional practices once we have taken the all important first step. But, the argument continues, the

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[9] See Care Not Killing (ch1 n76).

[10] See Not Dead Yet UK (ch1 n93).

[11] 2004 HL Select Committee Report Vol I (ch1 n49) paras91-103.

> additional practices are plainly unacceptable; therefore, the first step had better not be taken.[12]

Keown assesses the ‘logical’ argument by considering a hypothetical law which permits physician-assisted suicide in response to a competent patient who (i) makes a request and (ii) is terminally ill and experiencing unbearable suffering. Keown asserts that such a law would be the first step onto a slippery slope, by raising logical dilemmas. Under such a hypothetical law, he notes that if a competent patient’s request merely triggers a physician’s assessment of their suffering, then a logical extension would be to also relieve the unbearable suffering of incompetent patients, rather than exclude them simply because they cannot make a request to have their suffering assessed. If, on the other hand, a competent patient’s request is the primary requirement for assisted death then a logical extension would be to accede to all competent requests rather than requiring the patient to be suffering unbearably (or even at all).[13] Not all commentators, however, agree with Keown that this ‘logical’ dilemma is valid. Smith, for example, asserts that Keown’s arguments are flawed. Smith argues that the logical dilemma and risk of slippage raised by Keown only arise when unbearable suffering and competency are considered separately. If a law requires both elements together, then no slippage is likely, and it is possible to hold the line.[14]

6.2.2 *The empirical slippery slope argument*[15]

According to Rachels, the empirical form of the slippery slope argument (the ‘empirical’ argument) provides that:

> once certain practices are accepted, people shall in fact go on to accept other more questionable practices. [The ‘empirical’ argument] is simply a claim about what people will do and not a claim about what they are logically committed to. [T]his form of the argument [holds] that if we start off by killing people to put them out of extreme agony, we shall in fact end up killing them for other reasons, regardless of logic and nice distinctions.[16]

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[12] Rachels (ch3 n102)172-3.

[13] Keown (ch5 n24) 77.

[14] SW Smith, ‘Fallacies of the logical slippery slope in the debate on physician-assisted suicide and euthanasia’ (2005)13(2) Med.L.Rev 224,232.

[15] Also referred to as the ‘practical’ or ‘psychological’ slippery slope argument.

[16] Rachels (ch3 n102).

Enoch similarly describes the ‘empirical’ argument as follows:

> Once we allow voluntary euthanasia…we may (or will) fail to make the crucial distinction, and then we will reach the morally unacceptable outcome of allowing involuntary euthanasia; or perhaps even though we will make the relevant distinction, we will not act accordingly for some reason.[17]

Thus, the ‘empirical’ argument recognises the moral and legal distinctions between voluntary, non-voluntary,[18] and involuntary euthanasia, but as Lewis maintains, ‘[people] are bad at abiding by [those] distinction[s]’.[19]

Keown argues that the ‘empirical’ argument’s concerns are real. He asserts that even if a defensible line permitting voluntary euthanasia can be drawn in principle, a slide from voluntary to non-voluntary euthanasia will occur in practice, because the safeguards will inevitably be ineffective.[20] Keown asserts two mechanisms which would drive such slippage, and hence support the ‘empirical’ argument. Firstly, the legalisation of voluntary euthanasia would tend to change physician attitudes towards non-voluntary and involuntary euthanasia. Secondly, that if voluntary euthanasia is permitted under certain circumstances, then occurrences of non-voluntary euthanasia are more difficult to police than if voluntary euthanasia were not permitted at all. More specifically, Keown asserts that allowing voluntary euthanasia as a last resort would make it difficult to prevent from becoming an earlier resort.[21]

Several commentators have noted a slippage in relation to the Abortion Act 1967, of a nature which parallels the ‘empirical’ argument. In 1988, Keown observed that the Abortion Act had resulted in abortion being carried out in over 180,000 cases every year on request, and in most cases not on health grounds as required by the Act but rather on

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[17] D Enoch, ‘Once You Start Using Slippery Slope Arguments, You’re on a Very Slippery Slope’ (2001)21 Oxford J.Leg.Stud 629,631. For ‘voluntary euthanasia’, see ch1 n7, and for ‘involuntary euthanasia’, see text to ch1 n98.

[18] ‘Non-voluntary euthanasia’ (text to ch1 n98).

[19] Lewis (ch1 n177) 198.

[20] J Keown, ‘Euthanasia in the Netherlands: Sliding Down the Slippery Slope?’ (1995)9 Notre Dame J.L.Ethics&Pub.Pol’y 407,408.

[21] Keown (ch5 n24) 72.

social grounds.[22] Earlier, in 1974, Lord Habgood explicitly drew a parallel between abortion and euthanasia by noting that:

> The safeguards and assurances given when the [Abortion] Bill was passed have to a considerable extent been ignored…[one could expect] similarly far-reaching and potentially more dangerous consequences from legalised euthanasia.[23]

The same parallel was later supported in 1995 by Goff, when he stated that:

> An indication that there may well be no such defensible line may be drawn from experience of the legalisation of abortion in England which, though introduced for the main purpose of attacking the perceived evil of back street abortions, now extends to permit abortion in practically all circumstances.[24]

As with the ‘logical’ argument, not all commentators agree that the ‘empirical’ argument is valid. Jackson, for example, expresses scepticism for such an argument. She notes that:

> The argument suggests that although we might be able to distinguish paradigm cases at the top of the moral slope from those at the bottom, it would be very difficult to locate or police the line between acceptable and unacceptable practices towards the middle of the slope. Yet this ‘grey area’ problem exists whenever we attempt to regulate anything.[25]

6.2.3 *Slippery slope ‘mechanisms’*

The potential mechanisms for a slippery slope are numerous, and potentially unlimited. Commentators have provided several examples of such ‘mechanisms’, where the enactment of one law may make the enactment of a second law or the occurrence of some conduct more likely than if that first law weren’t enacted. One mechanism is that

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[22] J Keown, *Abortion, Doctors and the Law: Some Aspects of the Legal Regulation of Abortion in England from 1803 to 1982* (CUP 1988).

[23] Rt Rev JS Habgood, ‘Euthanasia – A Christian View’ (1974)3 J Royal Society Health 124, 126.

[24] R Goff, ‘A Matter of Life and Death’ (1995)3(1) Med.L.Rev 1,14.

[25] E Jackson, ‘Memorandum by Professor Emily Jackson, Chair of Medical Law, Queen Mary, University of London’ in Select Committee on the ADTI Bill 2004, *Assisted Dying for the Terminally Ill Bill [HL], Volume III - Evidence (Individual Submissions)* (2004-05, HL86-3) 52.

the first law may change public attitudes towards another law or behaviour, making it more likely.[26] A second mechanism is that several incremental changes in a law may each be small enough to be ignored by those who would otherwise be opposed, whilst collectively they have a significant detrimental impact.[27] A third mechanism exists when a law sets a pre-condition, where it is impossible to set a dividing line between the presence and absence of that condition.[28] In relation to assisted death, another set of mechanisms which may cause laws or practices to be broadened if assisted death were to be legalised are external factors, such as an aging population. Such mechanisms as those listed above are identified in the chapter, against each of the jurisdictions reviewed.

As noted above, those who argue against the legalisation of assisted death based on slippery slope concerns, may each have different reasons for believing that such a slippage will occur. They may point to different causal 'mechanisms' as being the drivers or the risk factors which encourage slippage, and which make it difficult to police a particular line.

The following section will examine the evidence for the 'logical' and 'empirical' arguments in the experience of the Dutch law on physician-assisted death. It will also examine whether there has been an increase in non-voluntary euthanasia in the Netherlands since it legalised voluntary euthanasia.

6.3 The Dutch experience

In the Netherlands, the categories of people and the types of suffering that may lawfully receive assisted death have gradually widened.[29] This section analyses whether this widening of the law provides evidence in support of any slippery slope concerns.[30]

Before Dutch legislation on assisted death came into force in 2002, Wachter noted that in cases decided between 1973 and 1983, Dutch courts had already applied two conditions for lawful euthanasia in the Netherlands — 'voluntary request' and

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[26] Volokh (n8) 1117; Smith (ch3 n271) 21.

[27] Volokh (n8) 1125.

[28] M Rino & D Whitman, 'The Camel's Nose is in the Tent: Rules, Theories and Slippery Slopes' (2003)51(2) UCLA Law Review 539,542 fn8 citing D Walton, *Slippery Slope Arguments* (Clarendon Press 1992) 3-7.

[29] Gorsuch (ch2 n54) 105-106.

[30] MA Somerville, 'Euthanasia's Slippery Slope: Once assisted suicide is legalized, it becomes impossible to limit the justifications for its use' (*The Mark*,17 March 2010).

‘unbearable suffering’. Wachter observed that from 1984, some courts had imposed additional conditions, such as that the patient had to have been suffering from an incurable disease, or that the patient’s death must not have imposed undue suffering on others.[31] In 1984, the Dutch Supreme Court in *Schoonheim* endorsed the KNMG[32] guidelines on the ‘due care’ criteria for assisted death, as was discussed in Chapter Five.[33] In doing so, *Schoonheim* effectively legalised euthanasia and assisted suicide in the Netherlands.

As will be demonstrated below, the sanctioning of assisted death by Dutch physicians gradually led to the legalisation of assisted death for increasingly broad categories of patients who did not meet the ‘due care’ criteria of the KNMG guidelines.[34] In a series of cases between 1985 and 2001, although the Dutch courts referred to the KNMG guidelines, they assessed each case according to its own circumstances. This approach gradually expanded the circumstances for lawful physician-assisted death.[35] This expansion of circumstances supports both the ‘logical’ and ‘empirical’ arguments noted above.

The ‘logical’ argument is supported by the Dutch courts having extended the ambit of ‘unbearable suffering’ to include mental anguish (i.e. suffering which is not associated with somatic or physical disease) by the early 1990s.[36] This extension is illustrated by two unrelated cases in 1992, in which the patients’ suffering was primarily not of a physical nature. In the first case, the patient suffered from depression.[37] In the second, the patient suffered from anorexia nervosa.[38] Dutch courts decided that in both cases, the suffering had been unbearable. In both cases, charges for assisted suicide against the physicians were dismissed and a defence of ‘necessity’ was accepted. The ‘logical’ argument is further exemplified in a third case – the 1994 Dutch Supreme Court case of *Chabot*. As was noted in Chapter Five, in *Chabot*, a psychiatrist had assisted the suicide

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[31] MAM de Wachter, ‘Active Euthanasia in the Netherlands’ (1989)262 JAMA 3316,3317.

[32] KNMG (ch5 n18).

[33] Schoonheim Case (ch5 n23). The Dutch cases cited in this section have been reported in Dutch, and their citation relies on a translation.

[34] BA Bostrom, ‘Euthanasia in the Netherlands: A Model for the United States?’ (1985)4 Issues L.&Med. 467,473.

[35] ibid 473.

[36] Hendin (ch5 n66) 48,135-36.

[37] *Rechtbank Rotterdam* [District Court of Rotterdam] 23 June 1992 reported in *Nederlandse Jurisprudentie* 1992 nr 664; affirmed on appeal by *Gerechtshof Den Haag* [Hague Court of Appeal] 18 December 1992 reported in TGR 1993/52 [both noted by Griffiths (ch5 n30) 80 fn123].

[38] *Rechtbank Almelo* [District Court of Almelo] 20 December 1991 reported in TGR 1992/19 [noted by Griffiths (ch5 n30) 80 fn123].

of a 50-year old woman who had intractable depression but without any concomitant physical illness.[39] The Court in *Chabot* affirmed that 'unbearable suffering' may consist of mental suffering alone, without involving a medical condition.[40]

The 1985 *Admiraal* case also supports the 'empirical' argument.[41] A physician (an anaesthetist) performed euthanasia on a 34-year-old woman named Karin who was suffering from multiple sclerosis.[42] Karin had lost all movement except for one hand, was barely able to swallow or speak, was losing her sight, and was in constant pain. Despite her condition, Karin was not classified as being terminally ill. The physician was prosecuted for euthanasia. A question raised at the trial was whether the physician's conduct had failed to meet the KNMG guidelines on the 'due care' criteria for an assisted death, as he had failed to consult an expert on multiple sclerosis (a neurologist). The District Court ruled that the doctor had been confronted by a situation of 'necessity', that he had carefully weighed the conflicting duties and interests against each other, and that in doing so he had made a justifiable choice. Although the physician had not consulted a neurologist, he had consulted the terminal care team at the hospital where he practised, and so was found to have complied with the requirements of careful practice.[43] On this basis, the physician was acquitted. The *Admiraal* case exemplifies the inherent potential for guidelines to be broadened through a consideration of individual circumstances, rather than an insistence on strict compliance.

Support for the 'empirical' argument is also illustrated by a 1986 Dutch case which accepted that a physician who succumbs to the pressures of a patient's distress may be excused from criminal liability. The case involved the euthanasia of Mrs M, a 73-year-old patient with advanced multiple sclerosis, by a physician who was also a friend of the patient. The Supreme Court rejected a defence of 'necessity', as the physician had not consulted a colleague in accordance with the KNMG guidelines.[44] Nevertheless, the Court held that both the dire physical and psychological distress of the

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[39] Chabot case (ch 5 n41).

[40] Griffiths (ch5 n30) 329-40.

[41] Admiraal Case, *Rechtbank Den Haag* [District Court of The Hague] 21 June 1985 reported in *Nederlandse Jurisprudentie* 1985 nr 709 [tr: as noted by Griffiths (ch5 n30) 66-67]; 'Abstract: HRG Feber, *De Wederwaardigheden van Artikel 293 van het Wetboek van Strafrecht vanaf 1981 tot Heden* (The Vicissitudes of Article 293 of the Penal Code from 1981 to the Present), in *Euthanasie Knelpunten in Een Discussie* (Euthanasia: Bottlenecks in a Discussion), 54-81 (G.A. Van Der Wal, ed., 1987)' (1988)3 Issues L.&Med. 455,465.

[42] Griffiths (ch5 n30) 66-67.

[43] R Cohen-Almagor*, Euthanasia in the Netherlands: The Policy and Practice of Mercy Killing* (Springer 2004), 42.

[44] ibid 44.

patient, and the resultant mental duress on the physician were mitigating factors against a conviction for euthanasia.[45] Once again, this illustrates a broadening of general principles when applied to specific circumstances.

A 1991 study of 26 euthanasia cases in the Netherlands by Gomez also found support for the 'empirical' argument. The study found that the 'due care' criteria in the KNMG guidelines were not being strictly followed. Gomez noted that (1) requirements such as 'unbearable suffering' were loosely interpreted, (2) alternatives were often not provided to patients so that euthanasia was not a 'last resort', (3) consulting physicians were not always used in euthanasia cases, and when they were, there was no way of assuring their independence from the attending physician, and (4) euthanasia cases were not routinely reported to the public prosecutor as required.[46] The 2005 case of *van Oijen*, in which the Dutch courts sentenced a physician leniently for involuntary euthanasia,[47] further corroborates the 'empirical' argument.[48] The case involved an 84-year-old patient whose physical condition had deteriorated terribly, before she then lapsed into a coma. The patient's condition was described as 'very exceptionally degrading' and she was expected to die within 48 hours. Although the patient had earlier expressed that she did not want euthanasia, her daughter had requested that she be assisted to die.[49] The physician gave the patient a lethal injection, soon after which she died. The Supreme Court found the physician guilty of murder. The Court held that not only was there no request for euthanasia, but that because the patient was in a coma, she was not suffering unbearably.[50] Nevertheless, the Supreme Court also accepted that the physician had made an 'error of judgement', and that he acted 'honourably and according to his conscience', showing compassion in what he considered to be in the interests of his patient.[51] For these reasons, the physician was merely given a one-week conditional prison sentence which was subject to a two-year probationary period.

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[45] *Hoge Raad* [Supreme Court] 21 October 1986 reported in *Nederlandse Jurisprudentie* 1987 nr 607 [reviewed in 'Nota Bene, The High Court of The Hague, Case No. 79065, October 21, 1986' (1988) 3 Issues L.&Med. 445].

[46] Gomez (ch5 n36).

[47] 'Involuntary euthanasia' (text to ch1 n98).

[48] van Oijen case, *Hoge Raad* [Supreme Court] 9 November 2004 reported in *Nederlandse Jurisprudentie* 2005 nr 217.

[49] T Sheldon, 'Dutch GP Found Guilty of Murder Faces No Penalty' (2001)322 BMJ 509.

[50] T Sheldon, 'Two test cases in Holland clarify law on murder and palliative care' (2004)329(7476) BMJ 1206.

[51] Smies (ch5 n49).

Further corroboration of the ‘logical’ argument is found in the expansion of the ambit for lawful physician-assisted death under the Dutch Act. As discussed in Chapter Five,[52] the Dutch Act allows physicians to perform euthanasia or assist with the suicides of a much wider group of people than that initially envisaged by the KNMG and the Dutch courts. Also as discussed in Chapter Five, the Dutch Act explicitly extended assisted death to minors aged between 12 and 16 years. Prior to the Dutch Act, such minors were not expressly given such rights. Since 2004, the RRCs have allowed those with the early onset of dementia, but who are otherwise competent, to request an assisted death on the basis that the prospect of a further loss of dignity constitutes ‘unbearable and hopeless suffering’. The Dutch Act also loosened the requirement for a ‘voluntary and well-considered request’, to include the advance declarations of incompetent patients. However, as discussed in Chapter Five, a request in an advance declaration is not an expression of a patient’s current wishes. Since it is not an expression of a person’s autonomous request at the time of assisted death, it is difficult to argue that this satisfies the ‘due care’ criteria in the Dutch Act. As an additional loosening of requirements since the Dutch Act — as of 2004, the RRCs have given legal effect to those advance declarations which specify dementia (including Alzheimer’s disease) as the medical condition covered.[53] In support of this, the requirement for ‘unbearable and hopeless suffering’ in the Dutch Act has been loosened to include ‘the unacceptable prospect of a further loss of dignity’ such as that which a patient feels during the early onset of dementia.

The *Groningen Protocol*, which has provided for lawful neonatal termination[54] since 2005, may also provide support for the ‘logical’ argument. Through recognition of the *Groningen Protocol* by the Dutch prosecution authorities, this extension to Dutch law demonstrates that what started off as voluntary euthanasia[55] for competent adult patients suffering unbearably due to a condition that cannot be improved, has been extended to non-voluntary euthanasia[56] for critically ill and severely disabled neonates suffering unbearably and experiencing a poor quality of life. The *Groningen Protocol* does not, however, provide support for the ‘empirical’ argument. Despite concerns that the Protocol would lead to a large increase in neonatal terminations, such cases have

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[52] See section 5.2.2.

[53] 2004 RRC Annual Report (ch5 n106).

[54] Discussed in section 5.2.3.

[55] ‘Voluntary euthanasia’ (ch1 n7).

[56] ‘Non-voluntary euthanasia’ (text to ch1 n98).

decreased from 10-15 per year in 1995[57] and 2001[58], to two per year in 2010.[59] Verhagen attributes this to a change in antenatal ultrasound screening practices in 2007, resulting in a greater number of critical health conditions being detected *in vitro*. [60] As summarised by Verhagen, 'This resulted in increased terminations of pregnancy and fewer instances of euthanasia'.[61]

In response to the 2003 *Sutorius* case,[62] discussed in Chapter Five, the KNMG established a committee ('Dijkhuis committee') to analyse the issues concerning patients who request assisted death because they are 'tired of living'. The Dijkhuis committee recommended that from a medical perspective some 'tired of living' cases would qualify for assisted death under existing standards of unbearable suffering despite the judgment in *Sutorius* stating that no such cases would qualify.[63] This illustrates the practical difficulties in setting a boundary for assisted death which prevents slippage. The Dijkhuis committee also differed from the Supreme Court in *Sutorius* in their opinion of whether doctors have the expertise to address suffering due to a non-medically classified disease or disorder.[64] The committee felt that doctors would have the necessary expertise in some cases.

In May 2010, a Dutch 'citizen's initiative' called *Uit Vrije Wil* [From Free Will] submitted a petition with over 116,000 signatures to the government, which called for anybody over the age of 70 to be able to request euthanasia, with no requirement to prove unbearable suffering.[65] The proposal was never acted upon, however, the ability of the proposal to raise so many endorsements itself supports concerns of a slippery slope. Under the 'logical' argument, the tabling of such a proposal is consistent with a shift in Dutch public opinion following the Dutch Act and earlier case law.

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[57] van der Heide (ch5 n131).

[58] Vrakking (ch5 n132).

[59] E Verhagen, 'The Groningen Protocol for newborn euthanasia: which way did the slippery slope tilt?' (2013)39(5) J Medical Ethics 293,294.

[60] ibid 294.

[61] ibid 295.

[62] Sutorius case (ch5 n53).

[63] *Op zoek naar normen voor het handelen van artsen bij vragen om hulp bij levensbeëindiging in geval van lijden aan het leven: rapport Commissie Dijkhuis* [The role of the physician in requests for assisted death from patients who are 'suffering from life': Report of the Dijkhuis Commission](KNMG 2004).

[64] See section 5.2.1.

[65] *Uit Vrije Wil* [From Free Will] <www.uitvrijewil.nu> accessed 16 December 2013.

Based on the discussion above, the Dutch experience indicates that multiple potential slippery slope mechanisms may exist in the Netherlands. Firstly, there is the imprecise requirement of ‘unbearable suffering’, whose boundary with being ‘tired of living’ is intrinsically difficult to define. Secondly, there is the shift in public attitudes which has apparently occurred once laws have been introduced.[66] The expansions and extensions in the Dutch law clearly support the slippery slope argument, be it the ‘logical’ or ‘empirical’ argument.

In addition to these mechanisms, there is also the argument to be considered that the legalisation of voluntary euthanasia in the Netherlands has resulted in an increase of non-voluntary euthanasia. In 1989, Fenigsen argued ‘that regulations promulgated by Dutch courts to control the practice [of lawful euthanasia] were widely ignored, and that euthanasia without informed consent of patients was common’.[67] Fenigsen’s argument was not supported by the subsequent findings of the Remmelink Commission in its 1990 Remmelink Survey.[68] The Remmelink Survey showed that termination of life by the administration of lethal drugs without explicit request from patients accounted for 1,000 out of 130,000 deaths (0.8%). A similar rate for the termination of life without request (0.7%) was noted in two subsequent government studies – the 1995 Van der Maas Survey,[69] and the 2001 Onwuteaka-Philipsen Survey.[70]

A follow-up study by van der Heide et al in 2005 (‘van der Heide study’), found that the rate of non-voluntary euthanasia had fallen to 0.4%.[71] However, the van der Heide study included only a death certificate review, whereas the previous three studies also included physician interviews and questionnaires. Despite this fourth study being more limited in scope, it is still worth noting that no evidence of an increase in non-voluntary euthanasia was found. It is submitted that across the four studies, there is no evidence that Dutch physicians are engaging more frequently in non-voluntary euthanasia since the Dutch Act came into force than beforehand, and hence no support for this aspect of the ‘empirical’ argument was found.

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[66] Keown (ch2 n389).

[67] R Fenigsen, ‘A Case Against Dutch Euthanasia’ (1989)19 Hastings Cent.Rep, Jan-Feb (supp) 22.

[68] The Remmelink Survey (ch5 n85). See also ch5 n83.

[69] The van der Maas Survey (ch5 n92-2).

[70] The Onwuteaka-Philipsen Survey (ch5 n92-3). This report provides a summary of data comparing the results of the 1990, 1995, and 2001 studies. The three Dutch government nationwide studies used similar methodology i.e. cross-sectional analyses of physician interviews, death-certificates, and questionnaire data.

[71] The van der Heide Study (ch5 n92-4).

In conclusion, prior to the Dutch Act coming into force, the slippery slope argument is evidenced in the Netherlands by the courts' willingness to overlook strict compliance with the law when considering the individual circumstances of each case, and to logically expand the circumstances which permit lawful euthanasia. Subsequent extension of the law, following the Dutch Act — to include minors, those with the early onset of dementia, and advance declarations of incompetent patients (including for reasons of dementia) — further supports the slippery slope argument. The 2005 *Groningen Protocol* also supports the argument. Within this slippage by the Netherlands, however, there is no evidence that there has been a post-legalisation increase in the rate of non-voluntary euthanasia. Thus, an argument that the legalisation of voluntary euthanasia in England and Wales would bring about a slide down a slippery slope to non-voluntary euthanasia is not supported by the Dutch experience.[72]

The following section will examine the extent to which experiences with the Belgian law on euthanasia support either the 'logical' or 'empirical' argument.

6.4 The Belgian experience

In considering medical practices under the Belgian Act, any evidence of the legal requirements for euthanasia being ignored by physicians, or of the Belgian authorities not enforcing the law, would support the 'empirical' argument.

The first official euthanasia case in Belgium involved a 39-year-old with multiple sclerosis who died by lethal injection within seven days of the Belgian Act coming into force.[73] This was despite the Act's requirement for a cooling off period of one month, for deaths that are not imminent. In this case, also, it is unclear whether the patient's attending physician had consulted a second independent physician, who is required under the Belgian Act to be either a specialist in the patient's disorder or a psychiatrist.[74] The CFCE[75] overlooked these failures, and instead placed emphasis on the fact that the patient had made repeated requests for euthanasia prior to the Belgian Act coming into force.[76]

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[72] Lewis (ch1 n177) 199,200.

[73] R Watson, 'First Belgian To Use New Euthanasia Law Provokes Storm of Protest' (2002)325 BMJ 854.

[74] A Osborn, 'Belgian Outcry Over First Mercy Killing Under New Law', *The Guardian* (London,9 October 2002).

[75] CFCE (ch5 n162).

[76] Cohen-Almagor (ch5 n176) 207.

Such disregard for the requirements of the Belgian Act was also found by a number of Belgian studies between 2006 and 2010, which in turn support the 'empirical' argument.

In the first study, Inghelbrecht et al surveyed Flemish nurses who cared for patients that had been assisted to die in 2006.[77] Despite a requirement under the Belgian Act that lethal medication be administered by a physician, this study found widespread instances where physicians had delegated this task to nurses, sometimes with the physician not even being present when the medication was administered. The study found that lethal medication was not only administered by nurses in 12% of voluntary euthanasia[78] cases, but also in 45% of non-voluntary euthanasia[79] cases.

In the second study, Smets et al surveyed Flemish physicians whose patients had died between June and November 2007. The study considered the reporting requirements under the Belgian Act. It found that nearly half of all euthanasia cases in Flanders between June and November 2007, were not reported to the CFCE.[80] The researchers further found that in 41.3% of euthanasia cases which were unreported, opioids or sedatives had been administered by a nurse rather than the physician, thus corroborating Inghelbrecht et al's study above.

In a third study, Chambaere et al reviewed Flemish death certificates between June and November 2007 (the same coverage as Smets et al's survey above). As noted in Chapter Five, this study found that 32% of euthanasia cases were carried out in the absence of a request or consent; mainly among patients aged 80 years or older who were incompetent due to either being in a coma, or suffering from dementia.[81]

In a fourth study by Van Wesemael et al, 132 LEIF[82] physicians were surveyed between May and September 2008 on their consultations over the previous 12 months.[83] The study found instances where the conduct of LEIF physicians had gone beyond the scope of their role as 'consultants'. Among 311 LEIF consultations between May and

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[77] E Inghelbrecht et al, 'The Role of Nurses in Physician-Assisted Deaths in Belgium' (2010)182(9) Can Med Assoc J 905.

[78] 'Voluntary euthanasia' (ch1 n7).

[79] 'Non-voluntary euthanasia' (text to ch1 n98).

[80] Smets (ch5 n203).

[81] Chambaere (ch5 n242).

[82] LEIF (ch5 n190).

[83] Van Wesemael (ch5 n191).

September 2008, in 26.7% of euthanasia cases, LEIF physicians had helped with the preparation of lethal medication, and in 23.5% of cases they (rather than the attending physician) had administered the lethal medication. This had occurred in the presence of the attending physician, but on occasions when the attending physician was unwilling to administer the medication, inexperienced, or unfamiliar with the drugs being used. As discussed in Chapter Five,[84] the LEIF network is supposed to merely provide physicians for the purposes of consultation. Although the Belgian Act does not specify that the attending physician should be the one to actually perform euthanasia (it can be done by any physician),[85] the roles between the attending physicians and the 'consultant' physicians from LEIF should not be reversed as this compromises the LEIF role.

Further support for the 'logical' argument is provided by the fact that since 2007, the Belgian Act has extended the law to those suffering from the mere 'anticipation of a future coma, loss of independence, or progressive dementia'. As discussed in Chapter Five, the CFCE has accepted that such anticipation can in itself constitute a medically futile condition of persistent and unbearable mental suffering 'here and now' that cannot be alleviated.[86]

In conclusion, the 'empirical' argument is supported by evidence in Belgium of a failure by physicians to strictly comply with the requirements of the Belgian Act, and the lack of enforcement by the Belgian authorities. Evidence of widespread non-voluntary euthanasia was found, but with no evidence that this had increased since the Belgian Act legalised voluntary euthanasia.[87] The 'logical' argument is supported by the CFCE having extended the legal boundaries of lawful euthanasia as noted in the previous paragraph.

Experience with the Death with Dignity Act ('DDA') in Oregon will be examined in the following section to determine whether there is support for either the 'logical' or 'empirical' argument.

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[84] See section 5.3.2.

[85] Van Wesemael (ch5 n191).

[86] '*La commission fédérale de contrôle et d'évaluation de l'euthanasie: Publications*' [CFCE: Publications] (*Service Public Fédéral:…: Soins de santé* [Federal Public Service:…: Healthcare]) <www.health.belgium.be/eportal/ Healthcare/Consultativebodies/ Commissions/Euthanasia/Publications/index.htm?fodnlang=fr> accessed 19 June 2014.

[87] See Bilsen (ch5 n233), and text to ch5 n234.

6.5 The Oregon experience

In Oregon, the phenomenon of ‘physician-shopping’ which was noted in Chapter Five provides support for the ‘empirical’ argument. The case of 85-year-old Kate Cheney in 1999 demonstrates that patients may be able to shop around until they obtain a positive mental health evaluation that will satisfy the DDA, and may possibly do so under pressure from others. The first psychiatrist in Kate Cheney’s case found her to be cognitively impaired, and possibly under pressure from her daughter to request a lethal prescription.[88] The second psychiatrist similarly found Kate to have had mild, potentially reversible mental depression.[89] However, Kate then consulted two other psychiatrists, who found her decision-making capacity to be intact.[90] She also obtained a further competency evaluation from a clinical psychologist, who noted that her choices ‘may be influenced by her family’s wishes and her daughter…may be somewhat coercive’.[91] The psychologist concluded, however, that there was ‘no severe impairment that would limit her ability to make a medical decision’.[92]

A second phenomenon in Oregon which may also support the ‘empirical’ argument is that many patients are shepherded to doctors affiliated with suicide advocacy groups[93] (also noted in Chapter Five). This is demonstrated by the 1999 case of 86-year-old Helen, who had been refused assistance by two physicians as they had each found her to be depressed. Her husband then contacted a suicide advocacy group Compassion and Choices, which referred Helen to the physician who then prescribed the lethal medication which enabled her death. The then director of Compassion and Choices, Barbara Coombs Lee, was quoted in a 1998 media interview as saying of the DDA and the patient’s ability to physician shop, that ‘[i]t really is a shift of power from the physician to the patient. If I get rebuffed by one doctor, I can go to another, because there are more physicians willing to do it now that it is legal and out in the open.’[94]

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[88] Barnett (ch5 n487).

[89] Foley, Hendin (ch5 n491) 156.

[90] Ganzini (ch5 n521).

[91] Barnett (ch5 n487) 5,7.

[92] ibid.

[93] Ganzini (ch5 n517) 1474.

[94] W Claiborne, ‘In Ore., Suicide Option Brings A Kinder Care * States Are Watching Physician-assisted Suicide Experience Closely. It Could Have An Impact On Dying Patients Nationwide’ *Washington Post* (Washington,3 May 1998).

Compassion and Choices was a key member of the Oregon Right to Die group which drafted the citizens initiative which became the DDA, as discussed in Chapter Five.[95]

It is argued that when physician-shopping occurs, there are no safeguards to ensure that each physician consulted is made aware of earlier findings. As the case of Helen highlights, even when a physician is aware of earlier consultations, there is no obligation on the physician to confer with those physicians who attended the patient previously. Helen's prescribing physician subsequently stated that, 'Before my patient died I didn't personally discuss the case with her regular physician and had only a very cursory contact with her second. I regret this.'[96] In relation to Helen's potential depression, the prescribing physician further conceded that, '[h]ad I felt there was a disagreement among the physicians about my patient's eligibility ... I would not have written the prescription'.[97]

In another case in 2000, the children of 65-year-old Joan Lucas contacted a suicide advocacy group to get the required help to end their mother's pain and suffering. Joan suffered from motor neurone disease. She had also been depressed, and had made numerous suicide attempts.[98] As the DDA does not specify how mental health evaluations should be carried out, a psychologist sent her a questionnaire by mail.[99] Joan's children read her the questionnaire and completed the form on her behalf, as she was physically unable to do so. Joan Lucas' case was well documented in the media and there is no suggestion of abuse in this instance. However, it does highlight the risk of abuse generally, due to a lack of safeguards. As noted by Physicians for Compassionate Care:

> With such unreliable information, the psychologist declared Joan Lucas was not depressed ... The psychologist made this determination despite the fact that studies published in the American Journal of Psychiatry[100] show 94% of Oregon psychiatrists don't feel confident they can determine when

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[95] See text to ch5 n448.

[96] Letter from Peter Reagan to Kathleen Foley (23 March 1999) qtd in Hendin & Foley (ch5 n475) 125.

[97] ibid 125.

[98] B Kettler, 'A death in the family: Stricken by ALS, Joan Lucas decides to die — then acts' *Mail Tribune* (Medford OR,25 June 2000) [qtd in 'Assisted-Suicide – a Response to Depression and Suicidal Ideation?' 20014(1) Physicians for Compassionate Care News.

[99] Hiscox (ch5 n474).

[100] Ganzini (ch5 n517).

> depression is affecting decisions about assisted suicide in a single visit, no less, no visit at all.[101]

The cases of Helen and Joan Lucas both highlight another potential risk that relates to physician-shopping. In both cases, the need to physician-shop was partly driven by a reluctance by many physicians to provide an assisted suicide. For the physician who ultimately agrees to help the increasingly desperate patient, their knowledge of such difficulties may compel them to follow through despite uncertainties as to whether a patient meets all of the DDA requirements. In an article for *The Lancet*, Helen's prescribing physician reflected on the case's personal impact for him due to the fondness he had come to have for Helen as a person. The physician notes that:

> The thought of Helen dying so soon was almost too much to bear, and only slightly less difficult was the knowledge that many very reasonable people would consider aiding in her death a crime. I found even worse the thought of disappointing this family. If I backed out, they'd feel about me the way they had [felt] about their previous doctor, that I had strung them along, and in a way, insulted them.[102]

Despite safeguards, this indicates the pressures which a physician may feel when assessing a patient against the requirements of the DDA.

Whilst the cases discussed above note the risks associated with physician-shopping, a 2007 study by Battin et al ('Battin study') found no statistical evidence that vulnerable groups had been abused under the DDA.[103] Battin et al chose to focus on vulnerable groups, based on a premise that whilst all patients are equally exposed to slippery slope pressures, any such pressures 'would selectively disfavour patients whose capacities for decision making are impaired, who are subject to social prejudice or who may have been socially conditioned to think of themselves as less deserving of care'.[104]

The Battin study analysed the annual reports of the Oregon Department of Human Services ('ODHS')[105] from 1997 to 2006, to see whether particular vulnerable groups

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[101] (2001)4(1) Physicians for Compassionate Care News <www.pccef.org/newsletters/vol4no1.htm> accessed 19 June 2014 (newsletter of the Physicians for Compassionate Care Education Foundation, whose platform is that physician-assisted suicide is wrong).

[102] Reagan (ch5 n492) 1266.

[103] Battin (ch 5 n480) 597.

[104] ibid 591.

[105] See ch5 n464.

were over-represented in the data.[106] The vulnerable groups considered were the elderly (defined as 85 years and older), women, the uninsured, people with low educational status, the poor, the physically disabled or chronically ill, patients with AIDS, minors, people with psychiatric illnesses (including depression), and people from racial or ethnic minorities. The only group for which any evidence of a heightened risk was found was those patients with AIDS. However, as the study notes, this finding was based on only six persons with AIDs having died under the DDA during the nine years which were analysed.[107]

In considering the elderly, the Battin study compared 18 to 64-year-olds with those aged 85 years and above. It found that patients aged between 18 and 64 years were over three times more likely than those over the age of 85 to receive physician-assisted suicide under the DDA. However, as noted by Finlay and George,[108] the study completely omitted 65 to 84-year-olds from its consideration. Had it compared 18 to 64-year-olds with those aged 65 years and above, then the results would have been quite different. The 2012 annual report of the Oregon Public Health Division (‘OPHD’) demonstrated that of 673 patients who died under the DDA between 1998 and 2012, 461 (68.5%) were aged 65 years or over, whereas the remaining 212 (31.5%) were aged between 18 and 64 years.[109] Further, the average age for DDA deaths recorded over this period was 71 years. It is argued that this statistical ‘over-representation’ of over-65s is not conclusive evidence of abuse. Some age related factors relate directly to vulnerability, such as not wanting to be a burden on family, friends or caregivers.[110] However, there are reasons why one would rationally expect the elderly to be more strongly represented than their younger peers, amongst those utilising the DDA. This is due to other age-related factors, such as a decreasing ability to participate in activities that made life enjoyable.[111]

In considering those who are not mentally competent, the Battin study states that none of the patients were determined to have had a mental illness which influenced their decision. In support of this statement, Battin et al referred to Ganzini et al’s 2000 study

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[106] Battin (ch 5 n480) 593-594.

[107] ibid 594.

[108] IG Finlay, R George, ‘Legal Physician-Assisted Suicide in Oregon and the Netherlands: Evidence Concerning the Impact on Patients in Vulnerable Groups; Another Perspective on Oregon’s Data’ (2011)37 J Medical Ethics 171,172.

[109] OPHD, 15th Annual Report (ch3 n242).

[110] See section 3.4.6 under *Patients as a burden on others*.

[111] OPHD, 15th Annual Report (ch3 n242).

which found that approximately 20% of requests for lethal prescription under the DDA came from depressed patients and that none progressed to physician-assisted suicide.[112] However, as the Battin study itself notes:

> Because not all patients who requested assistance were specifically evaluated by mental health professionals and because many cases of depression are missed in primary care, it is possible that some depressed patients received lethal prescriptions.[113]

Further, even when patients are referred for a mental health evaluation, a 2008 study by Ganzini et al found that some patients with depression were still not being detected. The study found that of 58 patients who had requested a lethal prescription, 18 patients were given clearance for physician-assisted suicide, of which three had treatable depression which went undiagnosed.[114] It is thus submitted that patients with any mental disorder, including depression, may be vulnerable under the DDA.

In considering those who are chronically ill, the Battin study observed that according to the annual reports of the OPHD, many patients who did not ingest their lethal prescriptions have subsequently lived longer than six months.[115] The 2012 annual report of the OPHD shows that the length of time between first request for physician-assisted suicide and death has ranged up to 1,009 days.[116] Whilst this range is due to the difficulties of giving an accurate prognosis (discussed in Chapter Five),[117] such difficulties place the chronically ill in a vulnerable position of being misdiagnosed as ‘terminal’ and constitutes a risk factor for the ‘empirical’ argument.

In conclusion, the phenomena of ‘physician-shopping’, and referrals by suicide advocacy groups to willing physicians, the fact that mental health evaluations are not compulsory, and the difficulties with estimating a six-month life expectancy are all mechanisms which may lead to the ‘empirical’ argument being realised. However, there is no evidence that such a slippage has yet occurred.

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[112] Ganzini (ch1 n78) 557.

[113] Battin (ch5 n480) 596.

[114] Ganzini (ch5 n514).

[115] See section 5.7.2.

[116] OPHD, 15th Annual Report (ch3 n242).

[117] See ch5 nn478-483.

The following section will examine whether experiences with the current law on end-of-life medical decisions in England and Wales support either a ‘logical’ or ‘empirical’ argument, of a nature similar to those asserted for euthanasia.

6.6 Have England and Wales already experienced a slide down a slippery slope?

As discussed in Chapter Four,[118] since Bland’s case in 1994,[119] English courts have tended to presume in favour of the withdrawal or withholding of life-sustaining treatment in cases involving patients in a PVS, or with a similarly severe condition. The English courts’ willingness to decide in favour of the withdrawal of such treatment may support both the ‘empirical’ and ‘logical’ argument.

In the *Frenchay* case, almost a year after Bland’s case, a court declaration had been granted at first instance without a full investigation into the facts, due to time constraints.[120] The patient had suffered severe brain damage due to a drug overdose, and had been diagnosed as being in a PVS. When his feeding tube became dislodged, the hospital obtained an urgent court declaration on short notice to lawfully refrain from replacing the life-sustaining feeding tube. However, the Official Solicitor then appealed to the Court of Appeal, on the grounds that there was insufficient time to consider the medical evidence provided, that two independent medical reports had not been obtained, and that there was some uncertainty about the patient being in a PVS.[121] The appeal was unsuccessful. Whilst the Court of Appeal in the *Frenchay* case acknowledged that Bland’s case had laid down a principle that the Official Solicitor should have adequate time to consider all medical evidence on behalf of the incompetent patient, Sir Thomas Bingham MR held that ‘I do not consider that it would be right to allow the appeal simply on the basis that there has not been an opportunity on behalf of S for there to be a full exploration of the facts which in other circumstances would be desirable.’[122] In then exploring the facts, the Court of Appeal also acknowledged that the medical

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[118] See section 4.3.3.

[119] Bland’s case (ch1 n12).

[120] *Frenchay* case (ch4 n65).

[121] ibid 410-412.

[122] ibid 410.

evidence concerning the extent and degree of a PVS was not as clear for S as it had been for Bland.[123]

Following Bland's case and in response to a recommendation of the 1994 House of Lords' Select Committee on Medical Ethics,[124] the RCP issued guidelines for the diagnosis of a PVS.[125] The RCP guidelines include a list of clinical criteria for the diagnosis of a PVS. Two English decisions in 1997 – *Re D*[126] and *Re H*[127] - made reference to the RCP guidelines when considering the withdrawal of ANH from two incompetent patients.

In *Re D*, the patient was found to be in a PVS despite not meeting one of the 'clinical features' of a PVS from the RCP guidelines – one which concerns the patient's responses to ice water, moving objects and other stimuli.[128] Based on the unanimous testimony of three key medical experts and the supporting testimony of the patient's attending nurses and family, Sir Stephen Brown P held that '[I]t must be recalled that every single witness…have all made it clear that this patient has no awareness whatsoever. She is, in the words of Lord Goff in *Bland*, suffering what he described as "a living death".'[129]

In *Re H*, which also came before Sir Stephen Brown P, the patient was similarly found to be in a PVS, despite not meeting the same 'clinical feature' concerning a patient's responses to stimuli that was considered in *Re D*.[130] As well as considering the unanimous testimony of the medical experts as to H's lack of awareness, Sir Stephen Brown also noted an alternative definition of a PVS which had been cited in the testimony of the medical experts, and which was satisfied by H. The alternative definition was sourced from the report of an international working party for the Royal Hospital for Neuro-Disability at Putney.[131] After noting this alternative definition,

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[123] ibid 411.

[124] *Report of the Select Committee on Medical Ethics* (ch3 n113).

[125] RCP, 'The Permanent Vegetative State' (ch4 n66).

[126] *Re D* (ch4 n69).

[127] *Re H* (ch4 n67).

[128] *Re D* (ch4 n69) 418.

[129] ibid 420.

[130] *Re H* (ch4 n67).

[131] ibid 38.

Sir Stephen Brown commented of the PVS condition that ‘This is, of course, a developing field for medical analysis’.[132]

It is concluded that the post-*Bland* case law reflects a relaxation of the criteria for the diagnosis of a PVS, and a move towards ‘quality of life’ standards[133] under which a patient may have some degree of awareness.[134] The cases above highlight that whilst *Bland* established a precedent for patients in a PVS, subsequent cases have favoured expert testimony on the awareness of individual patients, over compliance with a pre-defined set of clinical criteria. As had been noted above by Sir Stephen Brown P in *Re H*, the professional body of knowledge concerning PVS was still developing. This highlights the difficulties of establishing precise boundaries, and raises concerns of a potential empirical slippery slope. There is, however, no compelling evidence that such a slippage has yet occurred.

Concerns of a potential slippery slope in relation to incompetent patients have been heightened by guidance of the BMA from 1999. This guidance appears to extrapolate from the cases noted above in two respects, both of which are consistent with the ‘logical’ argument. Firstly, the BMA guidance builds upon the emphasis which the courts placed on awareness. The guidance not only endorses the withdrawal and withholding of life-sustaining treatment from patients in a PVS, but also extends this to patients with ‘other serious conditions’, such as those with severe dementia or those who have suffered a serious stroke.[135] The guidance is, however, imprecise as to what the ‘other serious conditions’ are, and the degree of ‘seriousness’ that would merit the withdrawal or withholding of ANH.[136] Secondly, the BMA guidance appears to draw conclusions from the emphasis which the courts have placed on expert medical opinion in preference to pre-defined guidelines. The guidance asserts that, in the absence of any serious conflict of medical opinion or uncertainty about a patient’s diagnosis, such decisions do not require legal review or a court declaration.[137]

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[132] ibid 38.

[133] Discussed in ch4.

[134] Meyers and Mason (ch4 n64) 274.

[135] See BMA, *Withholding and Withdrawing Life-prolonging Treatment* (ch4 n76)[21.4].

[136] J Keown, ‘Beyond Bland: a critique of the BMA guidance on withholding and withdrawing medical treatment’ (2000)20(1) Legal Studies 66,77.

[137] See BMA, *Withholding and Withdrawing Life-prolonging Treatment* (ch4 n76) [21.4]. Further editions of the guidance advise that additional safeguards should be in place before such treatment is withdrawn, but do not believe that such cases should be routinely subject to court review.

The following section will consider studies which have examined the rates of non-voluntary euthanasia[138] in several jurisdictions where euthanasia is illegal, and compared those rates with the Netherlands. It considers whether these studies provide support for the ‘empirical’ argument that the legalisation of voluntary euthanasia[139] in the Netherlands has resulted in a higher rate of non-voluntary euthanasia.

6.7 Multi-jurisdictional studies

In considering multiple studies which have analysed the rates of euthanasia across jurisdictions, it is noted that one must be careful when comparing the results from different studies because of potential differences in study designs and definitions used.[140] Nevertheless, the studies analysed in this section (conducted between 1996 and 2002) all purposively adopted a methodology similar to the Dutch nationwide studies.[141] They are all based on similar studies of death certificates, and the use of a similar interview questionnaire. This gives the findings from a comparison between the studies, a higher likelihood of validity.[142]

A further consideration when evaluating any single multi-jurisdictional study, as argued by Gorsuch, is that ‘different countries have different baseline (pre-legalisation) rates…because of unrelated cultural phenomena’.[143] Thus, even if the rate of non-voluntary euthanasia is higher in some jurisdictions where voluntary euthanasia is illegal than in jurisdictions where it is not, this difference may not be due to the legalisation alone.

A 1996 Australian survey by Kuhse, Singer et al[144] (‘Kuhse-Singer Survey’) does not support the ‘empirical’ argument that the rate of termination of life without request will tend to be higher in a country which allows euthanasia to be practised, than in a country which does not. Kuhse, Singer et al carried out an anonymous postal survey of 3,000 Australian doctors, who were randomly selected from a list of 27,000 on the Australian

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[138] ‘Non-voluntary euthanasia’ (text to ch1 n98).

[139] ‘Voluntary euthanasia’ (ch1 n7).

[140] van der Heide (ch5 n158) 345.

[141] Refer to n70.

[142] Smith (ch3 n271) 36.

[143] NM Gorsuch, ‘The Legalisation of Assisted Suicide and the Law of Unintended Consequences: A Review of the Dutch and Oregon Experiments and Leading Utilitarian Arguments for Legal Change’ (2004) Wis.L.Rev 1347,1395.

[144] H Kuhse, P Singer et al, ‘End-of-Life Decisions in Australian Medical Practice’ (1997)166(4) Med J Aust 191 (‘the Kuhse-Singer Survey’).

medical database. With the return of 1,918 completed questionnaires, the survey had a 64% response rate. The doctors were only asked about the most recent death they had attended. The researchers then adjusted the responses by the number of deaths each doctor had attended in that year.[145] The Kuhse-Singer Survey estimated that 1.7% of all deaths were the result of voluntary euthanasia,[146] and that 0.1% were the result of physician-assisted suicide. The survey also estimated that the rate of termination of life without request in Australia for that year was 3.5% of all deaths. This is a significantly higher rate than the Dutch rate of 0.7%.[147] Such a finding is contrary to Keown's argument that it is more likely for non-voluntary euthanasia[148] to occur where voluntary euthanasia is legal, as it is harder to regulate a practice that is permitted under prescribed conditions than one which is not permitted at all.[149] Kuhse, Singer et al suggested:

> It may be that, because existing laws prohibit the intentional termination of life, doctors are reluctant to discuss medical end-of-life decisions with their patients lest these decisions be construed as collaboration in euthanasia or in the intentional termination of life.[150]

Similarly, Otlowski attributed the higher rate of non-voluntary euthanasia in Australia found by the survey to the illegality in Australia of euthanasia. She argued that a lack of openness on the issues of euthanasia often results in physicians taking such decisions upon themselves.[151]

An alternative suggestion by Amarasekara and Bagaric is that, 'The prevalence of non-voluntary euthanasia [in Australia] is attributable not to the ban on [euthanasia] but to the faulty exercise of a discretion not to prosecute violations of the ban'.[152] They cite the cases of seven doctors in the Australian State of Victoria from the mid-1990s, who were not prosecuted for performing voluntary euthanasia illegally despite making

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[145] Seale (ch2 n148).

[146] 'Voluntary euthanasia' (ch1 n7).

[147] The Van der Maas Survey (ch5 n92-2). 2.4% of all deaths were the result of voluntary euthanasia, and 0.2% were the result of physician-assisted suicide: ibid.

[148] 'Non-voluntary euthanasia' (text to ch1 n98).

[149] Keown (ch5 n24) 146.

[150] The Kuhse-Singer Survey (n144) 196.

[151] M Otlowski, *Voluntary Euthanasia and the Common Law* (OUP 2000).

[152] The Kuhse-Singer Survey (n144) 196 cited by K Amarasekara and M Bagaric, 'The Legalisation of Euthanasia in the Netherlands: Lessons to be Learnt' (2001)27 Mon LR 179,191.

written admissions and receiving significant media publicity.[153] Thus, the legal prohibition on euthanasia did not influence the rate of 3.5% found.[154] Based on the Kuhse-Singer Survey and the subsequent commentary noted above, there is stronger support for a reverse 'empirical' slippery slope argument in which non-voluntary euthanasia becomes more common in jurisdictions (like Australia) where a ban on euthanasia exists but is not enforced, compared with jurisdictions (like the Netherlands) where euthanasia is permitted under prescribed regulations.

In 1998, prior to the legalisation of voluntary euthanasia in Belgium, Deliens, Mortier et al conducted a study on end-of-life medical decisions in Flanders ('Deliens-Mortier Study').[155] The study had a response rate of 52% (1,355 questionnaires).[156] It found a rate of 1.1% of all deaths for voluntary euthanasia and of 3.2% for the termination of life without request.[157] Mortier, Deliens et al noted 'that the figure [for non-voluntary euthanasia] is four to five times higher in Flanders than in the neighbouring Netherlands'.[158] They suggested as an explanation that 'in Belgium, the patient's autonomy is legally less clearly recognised and paternalistic medical practice appears to be more widely accepted'.[159] They also observed a lower likelihood of Belgian physicians than their Dutch counterparts to discuss with their patients, either decisions involving the withholding or withdrawal of treatment, or palliative measures intended to shorten the patient's life. They noted that this observation was consistent with their explanation noted above.[160] It is submitted that due to a culture of medical paternalism[161] in Belgium, it is difficult to compare Belgium with the Netherlands, a jurisdiction that is

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[153] Amarasekara and Bagaric (ibid) 191. cf. In England and Wales, the DPP's consent to prosecute is required for a crime of 'assisted suicide'. As discussed in ch2, there is often no prosecution due to public interest reasons.

[154] M Bagaric, 'The Kuhse-Singer Euthanasia Survey: Why it fails to Undermine the Slippery Slope Argument – Comparing Apples and Apples', (2002)9 Eur J Health L 229,236-8.

[155] The Deliens-Mortier Study (ch5 n153).

[156] ibid 1806.

[157] In the Netherlands, the Van der Maas Survey (ch5 n92-2) found that 2.4% of all deaths were the result of voluntary euthanasia, and 0.7% were the result of termination of life without request.

[158] Mortier, Deliens (ch5 n148) 179–95, 184 fn 17. Even in 2007, Chambaere's survey (ch5 n242) found that termination of life without request occurred more often in Flanders than in other jurisdictions, including the Netherlands.

[159] Mortier, Deliens (ch5 n148) 186–7.

[160] ibid 186-7.

[161] See section 3.3.8.

strongly influenced in end-of-life decisions by the ethical principles of autonomy[162] and self-determination.[163]

It has been argued that due to the methodology used in the Kuhse-Singer Survey and the Deliens-Mortier Study, the rates of non-voluntary euthanasia found may not be entirely accurate. The actual rates of termination of life without request in Australia and Belgium may have been lower.[164] Had either study included the ‘physician interview’ element of the Dutch nationwide studies, it would have been possible to verify the questionnaire data to ensure that the medical practices recorded as ‘termination of life without request’ were indeed of this nature. Further, Amarasekara notes that the Kuhse-Singer Survey did not differentiate between the doctrine of double effect[165] and a practice of relieving pain with an intention to cause death.[166] This same flaw is also true of the Deliens-Mortier Study which came after Amarasekara’s criticism. Due to this flaw, neither the Kuhse-Singer Survey nor the Deliens-Mortier Study are a reliable measure against which to assess the slippery slope argument concerning non-voluntary euthanasia.

A subsequent pan-European study of six countries by van der Heide et al (‘van der Heide Study’) obtained conflicting results.[167] The study considered data from Belgium (immediately prior to the legalisation of voluntary euthanasia), Denmark, Italy, the Netherlands, Sweden, and Switzerland between June 2001 and February 2002. The Netherlands was the only jurisdiction where both voluntary euthanasia and assisted suicide were legal at the time of the study. However, rather than finding that the Netherlands had a rate of termination of life without request which was either higher or lower than all of the other jurisdictions where euthanasia was prohibited, its rate was in the middle. The rates in Belgium (1.5%) and Denmark (0.67%) were higher than the Netherlands (0.6%), whilst Italy (0.06%) and Sweden (0.23%) had significantly lower rates. Thus, the van der Heide Study neither supports nor refutes the slippery slope argument concerning non-voluntary euthanasia.

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[162] See section 3.3.4.

[163] See section 3.3.2.

[164] A Fisher, JI Fleming et al, ‘Letter to the Editor’ (1997)166 Med J Aust 506.

[165] See section 3.3.6.

[166] K Amarasekara, ‘Euthanasia and the Quality of Legislative Safeguards’ (1997)23 Mon LR 1,15-16.

[167] The van der Heide Study (ch5 n92-4).

Seale's 2004-05 UK survey of end-of-life medical decisions ('Seale's UK Survey'), based on a similar methodology to the Kuhse-Singer Survey and the van der Heide Study, found a much lower rate for the termination of life without request for the UK (0.33% of all deaths) than either Kuhse, Singer et al had found in Australia (3.5%)[168] or van der Heide et al had found in the Netherlands (0.9%)[169]. Based on this one statistic alone, Seale's UK Survey provides support for the slippery slope argument concerning non-voluntary euthanasia by finding a rate for the UK which was lower than the Netherlands. However, the high rates which Seale found for 'symptom alleviation with possible life-shortening effect' (32.8%), and 'withholding or withdrawal of treatment' decisions (30.3%) may offer an alternative explanation, which calls that support for the 'empirical' argument into question. These two rates are both high when compared with Australia and the Netherlands.[170] As Kuhse asserted some years prior to Seale's UK Survey in 1988:

> laws prohibiting the intentional termination of life, but permitting the withholding or withdrawing of treatment and the administration of life-shortening palliative care, do not prevent doctors from intentionally ending the lives of some of their patients.[171]

Similarly, Griffiths asserts that 'To a considerable extent, a doctor can choose how to bring about a shortening of his patient's life and how to describe what it is that he has done.'[172] This explanation potentially weakens the support provided by Seale's UK Survey for the slippery slope argument concerning non-voluntary euthanasia, and indicates the general challenges of using comparative studies to assess such arguments.

6.8 Conclusion

From an analysis of specific jurisdictions, the chapter revealed that there is evidence to support the 'logical' argument in relation to euthanasia from both the Netherlands and

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[168] Seale (ch2 n227) 6(Table 2).

[169] ibid 7(Table 3).

[170] ibid 7(Table 3). cf. The Kuhse-Singer Survey (n144) showed a rate of 6.5% of all deaths for symptom alleviation with possible life-shortening effect, and a rate of 24.7% of all deaths for the withdrawal and withholding of treatment. The van der Maas Survey (ch5 n92-2) showed corresponding rates from its death certificate survey of 19.1% and 20.2%. These rates are lower than the 32.8% and 30.3% found by Seale.

[171] H Kuhse, 'From Intention to Consent: Learning from Experience with Euthanasia' in MP Battin et al (eds), *Physician Assisted Suicide: Expanding the Debate* (Routledge 1998), 263.

[172] J Griffiths, 'Comparative Reflections: Is the Dutch Case Unique?' in A Klijn et al (eds), *Regulating Physician-Negotiated Death* (Elsevier 2001), 203.

Belgium. There is also evidence from England and Wales to support a similar ‘logical’ slippery slope argument in relation to the withdrawal of treatment from incompetent patients. Evidence to support the ‘empirical’ argument in relation to euthanasia or assisted suicide was also found in the Netherlands, and Belgium. A review of multi-jurisdictional studies found evidence which refutes concerns of an ‘empirical’ slippery slope in relation to euthanasia, in which the legalisation of voluntary euthanasia causes an increase in non-voluntary euthanasia.

The chapter established that prior to the Dutch Act, there is evidence to support both the ‘logical’ and ‘empirical’ argument. In support of the ‘logical’ argument, the scope of unbearable suffering was extended over time. In support of the ‘empirical’ argument, the Dutch courts overlooked breaches of the KNMG guidelines, which purportedly set the ‘due care criteria’ for lawful physician-assisted death at that time. The expansion of lawful assisted death practices since the enactment of the Dutch Act further supports the ‘logical’ argument. The Dutch Act has extended the law on assisted death to minors and to patients experiencing the early onset of dementia, and includes the advance declarations of incompetent patients, even for reasons of dementia (including Alzheimer’s disease). Further support for the ‘logical’ argument is provided by the 2005 *Groningen Protocol*, which made neonatal termination lawful. However, no evidence was found from the Netherlands to support a slippery slope argument that the legalisation of euthanasia will lead to a rise in non-voluntary euthanasia.

In Belgium, the chapter found support for both the ‘logical’ and ‘empirical’ arguments. In support of the ‘logical’ argument, the CFCE has extended the legal boundaries of lawful euthanasia to those suffering from a mere anticipation of a future coma, loss of independence, or progressive dementia. In support of the ‘empirical’ argument, there was evidence of a regular contravention of the Belgian Act by physicians, and a lack of enforcement by Belgian authorities. Such contraventions include euthanasia being carried out by nurses and LEIF physicians.

In Oregon, no evidence of an actual slippage was found in relation to physician-assisted suicide. However, several slippery slope mechanisms were found which each increase the risk of an ‘empirical’ slippage. These are physician-shopping, referrals by suicide advocacy groups, the fact that mental health evaluations are not compulsory under the DDA, and the difficulties with estimating a six-month life-expectancy.

In England and Wales, no evidence of an actual slippage was found in relation to the law concerning the withdrawal and withholding of life-sustaining treatment from incompetent patients in a PVS. However, several slippery slope mechanisms were found which increase the risk of both a ‘logical’ and ‘empirical’ slippage. In relation to a ‘logical’ slippage, two mechanisms stem from the 1999 BMA guidance. The first is the extension of the withdrawal and withholding of life-sustaining treatment from patients in a PVS to patients with ‘other serious conditions’, and the second is an assertion that not all end-of-life medical decisions require review by a court. In relation to an ‘empirical’ slippage, these mechanisms are the reliance by courts on expert testimony on the awareness of each individual patient rather than a pre-defined set of clinical criteria, and the fact that medical opinion as to what constitutes a PVS is an area of medical knowledge which has been developing.

A key lesson from the Netherlands and Belgium is that assisted death laws which are not effectively regulated and enforced can easily lead to vulnerable people being abused.[173] Such a seemingly entrenched circumvention of laws with little if any prosecution can occur through a shift in attitudes, and has been exemplified in the UK’s experience with the Abortion Act. Although the Netherlands prior to the Dutch Act, and Belgium were both found to have allowed lapses in their requirements for lawful assisted death by physicians, no systematic abuse of the vulnerable has been found to have occurred in either jurisdiction. These experiences provide an argument for proceeding with caution to legalise assisted death in England and Wales, by developing law reforms which ensure effective safeguards and enforcement, and that contain mechanisms by which any slippages are detected and rectified.[174] Being mindful of the need for effective safeguards, the following chapter will conclude the thesis by making specific proposals for law reform on assisted death in England and Wales.

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[173] George (ch1 n92).

[174] J Downie, ‘The Contested Lessons of Euthanasia in the Netherlands’ (2000)8 Health L.J. 119,119.

Chapter 7. Conclusion

7.1 Introduction

The thesis has explored the debate on the legalisation of assisted death[1] in England and Wales. It was noted that the increasing media coverage on the assisted suicides of British subjects at Dignitas and high-profile cases like Tony Nicklinson[2] have fuelled the debate. The thesis has considered the three principal sources of controversy which were highlighted in Chapter One. These sources of controversy are, first, the suicide tourism of British citizens, secondly, the lack of clarification on the circumstances in which a person will be prosecuted for assisted suicide and, thirdly, inconsistencies between the law on assisted death and the law which governs legally permitted end-of-life medical decisions.

To address these controversies with law reform, the thesis has analysed the present law on assisted death and the social and ethical influences affecting its development. It has demonstrated how considerations of 'quality of life' are relevant to assisted death, and evaluated the laws of six foreign jurisdictions. The thesis has also examined the 'slippery slope' argument in three selected jurisdictions, and in England and Wales based on its current laws. The research has been conducted by employing three types of research methods. The social aspects of the law has been analysed by using a socio-legal approach. The doctrinal research method has been used to examine the current law and the legal developments in England and Wales, and comparative law has been used to examine and compare evidence from across the legal systems of selected jurisdictions.

Based on the research carried out in this thesis, it has been concluded that the current English law on assisted death is unsatisfactory, and in need of Parliamentary reform. The law does not address the needs of society, particularly of the terminally ill seeking an assisted death in England and Wales. To better meet the needs of society, it is proposed that there should be a law which permits physician-assisted suicide for terminally ill patients in England and Wales under strictly defined circumstances, with strict safeguards to protect potentially vulnerable people from abuse of the law. This

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[1] 'Assisted death', defined in section 1.1.

[2] See section 1.1.1, and section 2.2.2 under *Tony Nicklinson*.

proposed law reform, which responds to Research Question v) in Chapter One, will be discussed in section 7.3 below.

This chapter will recapitulate the key findings from the analysis within this thesis. This will be done by examining how far the research aims and objectives set out in Chapter One[3] have been met and the extent to which the research questions set out in that chapter[4] have been answered.

7.2 Research aims and objectives

The current prohibition on assisted suicide in England and Wales shows the influence of state paternalism. This was reflected in *Pretty* when the ECtHR held that any arguments premised on respect for patient autonomy were outweighed by the state's interest in 'preserving life and protecting the vulnerable'.[5] However, the trend towards individualism in England and Wales, as discussed in Chapter Three, has encouraged strong support for the ethical influences of autonomy and self-determination in end-of-life decisions. As observed in Chapter Two, the law's recognition of autonomy and self-determination is currently reflected in its position on suicide, the refusal of life-sustaining treatment, and the 'best interests' assessment of incompetent patients in cases concerning the withholding or withdrawal of life-sustaining treatment[6].

The ethical doctrine of sanctity of life alone cannot coherently be the rationale for the current prohibition on assisted death in England and Wales. As demonstrated in Chapter Two, neither legally permitted end-of-life medical decisions, nor the statute which decriminalised suicide, are based on the doctrine of sanctity of life. In Chapter Three, it was argued that the growing secularisation of England and Wales has resulted in increasingly liberal attitudes towards assisted death. As such, the orthodox religious values in English society on sanctity of life can no longer be relied upon to justify the current prohibition on assisted death.

It was established in Chapter Three that for assisted death to be permissible, it requires the approval of society. As the 1994 House of Lords' Select Committee on Medical Ethics stated, 'the issue of [assisted death] is one in which the interest of the individual

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[3] See section 1.3.

[4] See section 1.4.

[5] *Pretty* (ECtHR) (ch2 n22) 36-37,48, see section 2.2.2 under *Diane Pretty*.

[6] *Aintree NHS Trust* case (ch2 n306),see also section 4.3.4.

cannot be separated from the interest of society as a whole.'[7] Society's approval was also given emphasis in Baroness Hale's judgment in *Purdy*:

> It is not for society to tell people what to value about their own lives, [however at times, it] may be justifiable for society to insist that we value their lives even if they do not.[8]

Baroness Hale stressed the need for society, in certain situations, to value the lives of others and thus deny assisted suicide (e.g. those tired of living, those with physical disabilities) even if those others do not value their own lives. It is argued that the legal option of physician-assisted suicide should be restricted to those suffering from a terminal illness. If physician-assisted suicide is extended to others with non-terminal conditions, many people in society might be vulnerable under such a law. Their lives might be less valued in the eyes of society, by the very fact that such a medical option is made available to them.

As was demonstrated in Chapter Two, the public attitude in England and Wales is generally sympathetic towards assisted death for those with an unbearable terminal illness, but is not so for those wanting to die for less obvious reasons. As was noted in Chapter One, opinion polls show that less than 50% support assisted death being made available to those with 'severe physical disability'.[9] This was acknowledged by Baroness Hale in *Purdy*:

> [T]he British public have consistently supported assisted dying for people with a painful or unbearable incurable disease from which they will die, if they request it, while rejecting it for people with other reasons for wanting to die.[10]

Lord Hope in *Purdy* also made particular reference to the terminally ill. His Lordship distinguished assisted suicide cases that would ordinarily invite prosecution, from 'uncertain' cases involving the compassionate assistance of the terminally ill.[11] Thus, the line between what is legal and what is not with respect to physician-assisted suicide

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[7] *Report of the Select Committee on Medical Ethics* (ch3 n113) 48.

[8] *Purdy* (HL)(ch1 n31)[66].

[9] See section 1.3.

[10] *Purdy* (HL)(ch1 n31)[66].

[11] ibid [27],[54]. These assertions in the House of Lords reflect, consistently with the accepted judicial function, a judicial view of public morality.

should be drawn at terminal illness, with this marking the compromise between sanctity of life and public acceptability.

As noted in Chapter Two, the House of Lords judgment in *Purdy* addressed the right to private life under Article 8(1) of the ECHR. Purdy argued that Article 8(2) of the ECHR required the law to be accessible, foreseeable and precise in order for individuals to know in advance whether their conduct will be unlawful.[12] The House of Lords found that the consequences of assisting a suicide were not sufficiently foreseeable under section 2(4) of the SA 1961 with regard to the DPP's consent to prosecute, and that more guidance was required. In July 2009, the House of Lords held that in order to satisfy Article 8(2), the DPP needed to promulgate an offence-specific prosecution policy identifying the facts and circumstances which he will take into account in deciding whether or not to consent to a prosecution for assisted suicide under section 2(1) of the SA 1961.[13] The right to private life under Article 8(1) protects an individual's right to make autonomous choices regarding their quality of life, including the choice to end their life. This was plain in Baroness Hale's judgment: '[I]f the court is serious about protecting autonomy [then it must] accept that autonomous individuals have different views about what makes their lives worth living'.[14] Nevertheless, the DPP's prosecuting policy should not solely be based on one's right to autonomy. It should also protect the vulnerable, to ensure that a decision to end one's own life is not the result of pressure, coercion or duress. As Baroness Hale held: 'Clearly, the prime object must be to protect people who are vulnerable to all sorts of pressures…[and]…at the same time, the object must be to protect the right to exercise a genuinely autonomous choice.'[15] In this manner, some degree of state paternalism is warranted to prevent any potential for abuse and to protect the vulnerable in society.

Also as noted in Chapter Two, individual autonomy has been recognised in the DPP's Policy[16]. Prosecution for assisted suicide is unlikely if a person had made a rational, autonomous, and independent decision to end their own life. The DPP's Policy was intended to clarify how prosecutorial discretion is exercised, by providing specified circumstances where a prosecution for assisted suicide would tend to be either in, or not

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[12] ibid [28].

[13] ibid [56]. As noted in ch 2, the Daniel James case made it clear that the public interests factors in the CCP were not applicable to cases involving the assisted suicides of loved ones abroad.

[14] ibid [66].

[15] ibid [65].

[16] DPP's Policy (ch1 n34).

in, the public interest. Nevertheless, the Court of Appeal in Tony Nicklinson's case requested that the DPP amend his prosecuting policy to provide more clarity for healthcare professionals.[17] Under the DPP's Policy, physicians are currently deterred from getting involved in assisted suicides. The Court of Appeal in *Nicklinson* recognised that it is impossible to predict with any certainty whether a healthcare professional who assists a victim to commit suicide will be prosecuted or not. As a consequence, assisted suicide is an activity carried out by amateurs or inexperienced individuals in England and Wales. Not only is there a risk of a 'botched suicide' or of complications arising during the suicide which are poorly managed, but also family members and friends may be reluctantly compelled to assist in a loved one's suicide.[18] It was argued in Chapter Two that the involvement of healthcare professionals would give greater certainty of outcome, as they have the required medical knowledge and expertise to assist in suicides and to manage any complications during the suicide.

As argued in Chapter Three, it is unethical for the medical profession to bring patients to a state of extended suffering, and then abandon them in that state. If physicians are responsible for the prolonged unbearable pain and suffering caused by medical advances, then they should also be able to assist a patient to end such prolonged pain and suffering. Public opinion surveys in the UK show majority support for physician-assisted suicide. A 2010 survey found 74% of its respondents supporting physician-assisted suicide for the terminally ill.[19] Nevertheless, studies on assisted death discussed in Chapter Two, found that only between one-third and two-fifths of doctors favour such a permissive approach to assisted suicide for patients suffering from a terminal illness.[20] Also as noted, a recent survey of doctors in the UK showed that only 24.9% of physicians are willing to perform physician-assisted suicide.[21] Physicians are generally concerned about the impact of physician-assisted suicide on the relationship with their patients, and on the relationship between the medical profession and society in general. Chapter Three also determined that the medical profession in England and Wales, as represented by the GMC and the BMA, is against the legalisation of physician-assisted suicide as it goes against the underlying ethics of medicine.

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[17] *Nicklinson* (CA)(ch1 n10).

[18] 'Kay Gilderdale: A Devoted Mother' (ch1 n38).

[19] 'Assisted Suicide Survey: 8-10 January 2010' (ch2 n135).

[20] Seale (ch2 n173); Lee (ch2 n174).

[21] McCormack (ch2 n380).

It has, however, been concluded in this thesis that the legalisation of physician-assisted suicide will not undermine the integrity of the medical profession. A physician's involvement in their patient's death should be judged in the context of all the medical interventions made during the patient's terminal illness. As demonstrated in Chapter Two, despite end-of-life medical decisions which involve an 'acts and omissions' distinction or a 'double effect', such decisions have not undermined the public's trust in physicians. Further, the 'acts and omissions' distinction and the 'doctrine of double effect' do not prevent a physician from intentionally ending the life of a patient. In the case of the 'acts and omissions' distinction, a physician is allowed to withhold or withdraw life-sustaining treatment from an incompetent patient (in the absence of the patient's prior request or consent), effectively causing the patient to die slowly from starvation rather than from their underlying medical condition. Seale's 2007-2008 survey on end-of-life medical decisions in the UK showed that 21.8% of such deaths involved the withholding or withdrawal of life-sustaining treatment, and a further 17.1% of such deaths involved a medical decision with a 'double effect'.[22] Medical decisions with a 'double effect' involve those where a physician administers palliative medication which has a possible life-shortening effect. In such instances, the physician may not solely have an intention to relieve suffering but may also have an intention to hasten death. This was evidenced by Seale's survey, which found that physicians had both an intention to alleviate suffering and an intention to hasten death in 2% of the 17.1% of deaths noted above that involved a 'double effect'. End-of-life medical decisions involving the 'acts and omissions' distinction or a 'double effect' promote medical paternalism, rather than the autonomous wishes of a patient. As noted in Chapter Six, these might also be used to conceal non-voluntary euthanasia.[23]

As demonstrated in Chapter Five, the KNMG[24] has always supported physician-assisted death in the Netherlands. In respect of Belgium, the Belgian Act[25] did not at first command the support and approval of the Belgian medical profession. The Belgian medical profession's *CMD* initially continued to prohibit physicians from assisting patients to die. In time, however, it was amended to complement the Belgian Act. Physicians are now required to inform patients of all possible treatment options and to provide the relevant assistance for euthanasia. As with Belgium, it is expected that the

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[22] Seale (ch2 n148).

[23] See text to ch6 n171.

[24] KNMG (ch5 n18).

[25] Belgian Act (ch5 n161).

GMC and the BMA in England and Wales would make similar amendments to their respective codes of practice and medical guidelines, to support and complement any law reform that permits the participation of physicians in assisting suicide. As in Oregon, however, it should be anticipated that patients might still have difficulties finding a willing physician.

In Chapter Three, it was accepted that a request for physician-assisted suicide should trigger a medical investigation into other treatment options, such as palliative care. It was demonstrated that a number of remedies available through palliative care, such as symptom control, treating depression and improving social support, may reduce the desire for a hastened death in people with a progressive incurable illness. Studies in the UK have shown that suicidal patients who have expressed a strong desire for death, have been known to change their views once given high-quality palliative care. The practice of investigating other treatment options forms part of Oregon's legal framework on physician-assisted suicide under the DDA, discussed in Chapter Five. The annual reports of the OPHD consistently show that over 90% of patients receiving a lethal prescription had previously been referred to and enrolled in hospice care. In contrast, in the Netherlands, 'euthanasia as a last resort' often included cases where palliative care treatment could have alleviated a patient's suffering, but where such treatment was simply declined by them. As noted in Chapter Five, the practice of euthanasia in the Netherlands was often used as an alternative to palliative care.[26]

It was recognised in Chapter Three that not all terminally ill patients in England and Wales currently have access to effective palliative care or hospices.[27] It was also acknowledged that there have been serious shortfalls in palliative care training and practice. This raised concerns not only of the lack of expertise in palliative care, but also of its adequacy. It has been concluded in this thesis that a law which permits physician-assisted suicide will not meet the needs of society, if it operates against a backdrop of inadequate palliative care. There would need to be further development and improvement in palliative care treatment in England and Wales to adequately support such a law. As observed in Chapter Five, Belgium and Oregon both made advancements in palliative care treatment as an adjunct to legalising assisted death. In Oregon, the legalisation of physician-assisted suicide led to more training and interest by physicians in palliative care. In Belgium, the measures taken to promote palliative care were more

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[26] See text to ch5 n88.

[27] See text to ch3 nn229-230.

deliberate and extensive. The Belgian PCA was not only enacted around the same time as the Belgian Act, but the Belgian MDB, which endorsed the Belgian Act, stressed that palliative care had to be exhausted before euthanasia was resorted to.[28] As a consequence, every Belgian hospital has a palliative care team, and palliative home care is available throughout the country. In respect of the Netherlands, although the Dutch Act[29] does not mention the need for palliative care treatment, the Dutch RRCs have stressed in their annual reports that physicians should inform patients of the palliative care options that are available to relieve pain and suffering.

Chapter Three further established that despite physicians doing everything medically possible to minimise the distress and discomfort of a terminally ill patient through palliative care, their terminal illness may still involve intolerable pain and suffering beyond the scope of optimal palliative care. Such care may not be able to provide total relief for all patients.[30] In addition, some terminal degenerative conditions involve a decline in physical integrity and functional ability, beyond what patients perceive to be dignified bounds. It was also noted that the inability to maintain control or independence while dying is a fundamental loss of dignity for the terminally ill which palliative care may not be able to address. As an option of last resort, physician-assisted suicide would provide an assurance to the terminally ill that they are able to depend on their physicians to help them achieve a peaceful and dignified death.

As demonstrated in Chapter Three, depression is strongly associated with a terminally ill patient’s request for assisted death. Clinical depression is likely to impair a patient’s competence and decision-making capacity. According to a recent Dutch study, cancer patients with a depressed mood were four times more likely to request euthanasia.[31] In spite of this, physicians in England and Wales often fail to detect depression amongst terminally ill patients. A 2000 study in the UK showed that even physicians who were trained in depression recognised it in only 39% of patients who were known to have depression.[32] As observed in Chapter Five, Dutch commentators also acknowledge that physicians are generally unable to assess when patients have psychiatric disorders that may be interfering with their judgement.[33] Thus, to meet the needs of these vulnerable

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[28] See text to ch5 n220.

[29] Dutch Act (ch5 n62).

[30] RCP, ‘Principles of pain control in palliative care for adults’ (ch3 n240).

[31] van der Lee (ch5 n104).

[32] Thompson (ch3 n295).

[33] Hendin (ch5 n14) 237.

patients, it has been concluded that any law which permits physician-assisted suicide should also include a mandatory mental health evaluation. Terminally ill patients may also be indirectly pressured by family members to request an assisted death, in order to spare them financial or emotional strain. It has been accepted in this thesis that to meet the needs of the vulnerable members of society, palliative care treatment should have to be explored and exhausted as an option before resorting to physician-assisted suicide. The scope of palliative care includes measures to relieve others of burden, and strengthen relationships with loved ones.[34]

It was demonstrated in Chapter Four that under common law, English courts have been allowing the withdrawal or withholding of life-sustaining treatment from incompetent patients based on a ‘best interests’ assessment that reflects a paternalistic quality of life judgement by physicians and the courts. However, a ‘best interests’ assessment under the MCA 2005 promotes patient autonomy. It includes, where possible, a consideration of an incompetent patient’s previously expressed wishes and feelings about life-sustaining treatment. The Supreme Court decision in the *Aintree NHS Trust* case[35] affirmed that a ‘best interests’ assessment under the MCA 2005 requires a patient’s subjective interests to be considered, an assessment which is in line with a ‘substituted judgement’ standard.[36] It has also been accepted in this thesis that a ‘best interests’ assessment which is based on a patient’s subjective view is in effect a subjective evaluation of ‘quality of life’.[37] Thus, a law permitting physician-assisted suicide for competent patients who are terminally ill should also be based on a subjective evaluation of quality of life.

As established in Chapter Four, individuals seeking to end their lives do so based on a personal assessment of their quality of life. This is evident from the range of medical conditions suffered by Britons who have sought an assisted suicide at the Swiss right-to-die organisation, Dignitas. Although physicians are often the ones to make quality of life judgements in treatment decisions concerning the terminally ill, it has been concluded in this thesis that such quality of life assessments should be based on a patient’s subjective experiences. As observed in Chapter Three, due to a patient’s ability to adapt to illness (the ‘response shift’ phenomenon), their quality of life may change

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[34] Singer (ch3 n305).

[35] *Aintree NHS Trust* case (ch2 n306).

[36] See text to ch4 nn99-100.

[37] ibid.

during the course of terminal illness.[38] It was also noted that this ability to adapt to illness may be influenced by effective palliative care treatment. As a person's quality of life often changes during the course of terminal illness, a patient's subjective evaluation would best describe and define their quality of life. The *Aintree NHS Trust* case,[39] as mentioned above, also emphasised the subjective interests and views of a patient when deciding on the potential withdrawal or withholding of life-sustaining treatment from incompetent patients. There are, however, acknowledged difficulties measuring quality of life at the end of life using subjective measurement instruments. Patients may be too ill to complete such an assessment. Under such circumstances, doctors and family members may make an assessment of the patient's quality of life on their behalf. However, it was identified that such assessments are less accurate for the more subjective aspects of a patient's life.[40] It has accordingly been concluded in this thesis that such third party or proxy assessments would be inappropriate for a law permitting physician-assisted suicide, which should be entirely based on a terminally ill patient's subjective assessment of their quality of life.

Chapter Three established that the population of the UK is rapidly ageing. 'The elderly' (people aged 65 and over) are projected to increase to 12.7 million in 2018, and reach 16.9 million by 2035.[41] Studies demonstrate that the elderly often associate dignity in old age with autonomy and independence. They fear a poor quality of life and an undignified prolongation of death due to advances in medicine. As a consequence, a recent opinion poll found that 90% of the elderly feel that assisted suicide should be legalised for people with terminal illness.[42] These concerns of the elderly in the UK can be matched with those of the elderly in Oregon. As noted in Chapter Five, the annual reports of the OPHD consistently show that physician-assisted suicide under the DDA is predominantly utilised by the elderly[43] who have concerns with a loss of autonomy, a decreasing ability to enjoy life, the loss of dignity, and being a burden to others.[44]

It was demonstrated in Chapter Three that the elderly in the UK may already be under indirect pressure to desire an assisted death. According to studies, many elderly people

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[38] See text to ch3 n226; see also section 4.4.1 under *An objective professional evaluation*.

[39] *Aintree NHS Trust* case (ch2 n306).

[40] See text to ch4 n177.

[41] See text to ch3 n37.

[42] See text to ch3 n31.

[43] See text to ch5 nn550-552.

[44] See text to ch5 nn 554-557.

in the UK experience abuse; especially psychological abuse and neglect.[45] Further, as the opportunity to go into a hospice appears statistically to decline with age, the elderly do not have equal access to palliative care, thus adding further pressure on some elderly individuals.[46] Inadequate care and support for older people (over-75s) at the end of their lives has also been documented by various government reports. One report in particular criticised the NHS for treating elderly people without compassion, and for condemning many to die in unnecessary pain, indignity and distress.[47] It has been concluded in this thesis that these existing circumstances could make elderly people vulnerable, and desire an assisted death in circumstances where palliative care might otherwise provide relief. Any legalisation of physician-assisted suicide in England and Wales will need to address such prejudices towards the elderly, if it is to protect them from abuse.

Based on the experience of the Dutch law on euthanasia that has spanned over more than 30 years, Chapter Six found no evidence that the legalisation of voluntary euthanasia led to an increase in the rates of non-voluntary euthanasia[48] in the Netherlands.[49] Thus, this argument, which is often tendered by those opposed to the legalisation of assisted death, is entirely speculative. It was, however, noted in Chapter Five that even after euthanasia was legalised in Belgium, Belgian physicians did not completely abandon their pre-existing practice of non-voluntary euthanasia.[50] In these cases, communication with patients had been impossible due to a sudden deterioration in the patient’s illness, or communication had been deferred for too long.[51] In Flanders, non-voluntary euthanasia occurred mainly among patients 80 years of age or older, who were in a coma or suffering from dementia.[52] This approach by Belgian physicians demonstrates a highly paternalistic attitude in which physicians apply their own quality of life judgement to a patient. Nevertheless, the rate of non-voluntary euthanasia in Belgium has dropped since 1998.[53]

Based on the findings in this research, it is accepted that there is indeed a case for change in the law on assisted death in England and Wales. The present status quo is

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[45] See text to ch3 n309.

[46] See text to ch3 nn230-231.

[47] See text to ch3 n310.

[48] ‘Non-voluntary euthanasia’ (text to ch1 n98).

[49] See text to ch6 nn67-71.

[50] Bilsen (ch5 n233).

[51] See text to ch5 n237.

[52] Chambaere (ch5 n242).

[53] See text to ch5 n234.

unsatisfactory, as the DPP's Policy does nothing more than reinforce the current law that assisted suicide is a crime. Despite the prospect of the DPP's Policy being developed further to clarify the law in respect of those healthcare professionals who assist in suicides,[54] it is proposed that there should be a law which permits physician-assisted suicide for terminally ill patients. As noted in Chapter Three, such a law could be justified by the ethical measures of deontology and consequentialism.[55] The law permitting physician-assisted suicide should be restricted to competent patients who are terminally ill, who find themselves suffering unbearably and experiencing a poor and unacceptable quality of life due to their terminal illness. Such patients should be allowed to make an autonomous request for assisted suicide, based on their own subjective evaluation of their quality of life. There should also be adequate and stringent safeguards to protect the vulnerable in society and to prevent abuse of the law.

7.3 Research questions

Based on the analysis of the preceding chapters, the research questions posed in Chapter One will now be answered in turn.

Research Question i)

Is the current law on assisted death in England and Wales satisfactory?
i.e. whether the law meets the needs of society in general and of individuals who competently decide that they do not wish to continue living, whether the law is consistent and coherent, and whether the law is legally and morally defensible.

It is concluded in this thesis that the present law is unsatisfactory for the following reasons.

With regard to the terminally ill, the current law is out of step with public opinion. This is demonstrated by recent public opinion polls in the UK which have shown a high level of support for legalising assisted death for the terminally ill. The *BSA* surveys, discussed in Chapter Two, have consistently found that 80% of respondents believe that assisted death should be allowed for terminally ill patients.[56] With regard to those who are not terminally ill, the current law is not so out of step. The *BSA* surveys found that of the

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[54] See text to ch2 nn166-167.

[55] See section 3.3.5.

[56] See text to ch2 nn137-139.

same respondents, only 45% thought it should be available to people with incurable but non-terminal illness.[57]

The large numbers of British citizens seeking an assisted suicide at Dignitas indicates that the law prohibiting assisted death in England and Wales is unsatisfactory. As noted in Chapter One, recent figures show that approximately 215 Britons have been helped to end their lives at Dignitas, whilst 821 other Britons were registered with Dignitas at the end of 2012.[58] The public reaction to increasing media coverage of these assisted suicides is also evidence that the law is unsatisfactory.

It has been noted in this thesis that, in one sense, due to a patient's right to refuse life-sustaining treatment, a competent patient can already achieve an assisted suicide with a physician's assistance. As observed in Chapter Two, physicians are required by law to discontinue life-sustaining treatment from a competent patient who has made an autonomous refusal for such treatment.[59] It is morally indefensible that any competent patient is permitted to die of starvation and dehydration by refusing life-sustaining treatment, yet is prevented from ending their life more directly and humanely through the ingestion of a lethal medication prescribed by a physician.

The cases of *Pretty*[60] and *Re B*[61] also demonstrate the inconsistency in the current English law on assisted death. Ms B who was not terminally ill, was allowed by the court to refuse a life-sustaining ventilator which was keeping her alive, whilst Mrs Pretty who was terminally ill, was denied a court order permitting her husband to assist her to travel abroad to Dignitas for an assisted suicide.

Further evidence of inconsistency in the current law is demonstrated by the English courts adopting the 'doctrine of double effect' and the 'acts and omissions' distinction, to differentiate permissible end-of-life medical decisions from acts of assisted death. Both the 'doctrine of double effect' and 'acts and omissions' distinction merely re-describe 'indirect euthanasia' and 'non-voluntary euthanasia'[62] in medical terms. Physicians in England and Wales may be using these permitted practices as a guise for practising euthanasia with no proper supervision or safeguards. As suggested in Chapter

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[57] ibid.

[58] See text to ch1 nn17-19.

[59] See text to ch2 n244.

[60] *Pretty* (HL)(ch1 n41).

[61] *Re B (Adult: Refusal of Medical Treatment)* (ch1 n42).

[62] 'Non-voluntary euthanasia' (text to ch1 n98).

Six, the prohibition on euthanasia in the UK may have encouraged doctors to terminate life in ways which are more difficult to detect.[63] Laws permitting the administration of life-shortening palliative care and the withholding or withdrawal of life-sustaining treatment do not prevent physicians from intentionally ending the lives of some of their patients.[64] Seale's 2004-2005 survey on end-of-life medical decisions showed that the administration of life-shortening palliative care and the withholding or withdrawal of life-sustaining treatment were widespread practices in the UK, with an estimated 33% and 30%, respectively, having had their lives ended this way every year.[65] It is argued that these widespread practices are the result of a culture of medical paternalism that is encouraged by the absence of a law permitting physician-assisted death.

Seale's 2007-2008 survey also found that 0.5% of all annual deaths in the UK are the result of euthanasia by physicians – 0.2% being cases of voluntary euthanasia,[66] and 0.3% being cases of non-voluntary euthanasia.[67] Seale's survey shows that in the absence of a legislative scheme to regulate assisted death, unlawful deaths are currently being facilitated by doctors without any appropriate safeguards, thus placing the vulnerable at risk. This is further evidence that the current law on assisted death in England and Wales does not meet the needs of society. As noted in Chapters Five and Six, studies in Germany[68], Australia,[69] and Belgium[70] have similarly found that a law against euthanasia does not deter all physicians from performing not only voluntary euthanasia but non-voluntary euthanasia as well.[71]

As demonstrated in Chapter Two, the law on assisted suicide in England and Wales lacks coherence. The DPP's Policy neither decriminalises assisted suicide, nor provides an assurance of immunity from prosecution.[72] Nonetheless, there have been no prosecutions for assisted suicide since the policy came into effect. The DPP's decision to not prosecute cases that satisfy the factors against prosecution has, in addition,

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[63] See text to ch6 nn168-172.

[64] Kuhse (ch6 n171).

[65] Seale (ch2 n227). See ch6 nn168-170.

[66] 'Voluntary euthanasia' (ch1 n7).

[67] Seale (ch2 n148).

[68] Schildmann (ch5 n332).

[69] The Kuhse-Singer Survey (ch6 n144).

[70] The Deliens-Mortier Study (ch5 n153).

[71] See section 6.7.

[72] DPP's Policy (ch1 n34) para6.

undermined society's respect for the law on assisted suicide,[73] and led to a public perception that assisted suicides that meet the policy criteria stipulated in the DPP's Policy are decriminalised.[74]

Research Question ii)

Have the recent legal developments on assisted death addressed the needs of society and the concerns of those seeking an assisted death in England and Wales?

It is concluded in this thesis that the recent legal developments have not addressed the needs of society, and the concerns of those seeking an assisted death in England and Wales. All of the following reasons support this conclusion.

As observed in Chapter Two, the DPP's Policy makes a prosecution unlikely to be in the public interest where a person compassionately assists a loved-one, who has made a voluntary, clear, settled and informed choice to die.[75] However, investigations pursuant to the DPP's Policy to consider the victim's settled decision to die and the suspect's motivation, are carried out only after the victim's death.[76] This inherent limitation is because the decision to prosecute cannot be made in advance. Thus, there are no prospective safeguards in place to protect those who might be vulnerable, particularly those who might be under pressure from others to end their lives.

The DPP's Policy makes it is difficult to obtain practical assistance in suicide within England and Wales. The policy specifically deters healthcare professionals from assisting patients.[77] However, their involvement would give greater certainty of outcome, lower the risk of botched suicides,[78] and reduce potential suffering during the suicide itself. The public-interest factors also prevent any individuals or organisations from providing any expert information or advice, and prohibit anyone from providing specific information via a website or publication.[79] As a result, there is no possibility for organisations such as the German Society for Humane Death or Dignitate Deutschland to support people in need of suicide assistance, by either providing information on drugs

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[73] *Report of the Commission on Assisted Dying* (ch1 n51) 93.

[74] Gibb ch2 n214.

[75] DPP's Policy (ch1 n34) para45(1)-(2).

[76] See text to ch2 n194.

[77] See text to ch2 n146.

[78] 'Kay Gilderdale: A Devoted Mother' (ch1 n38).

[79] See text to ch2 nn196-197.

and dosages necessary for a painless death, or by facilitating suicide tourism to Dignitas.[80]

The DPP's Policy has ensured that suicide assistance provided in England and Wales remains an activity carried out only by inexperienced individuals. As with the current position in Germany, patients in England and Wales depend on the assistance of people who are not medically trained to assist in their suicides. Amateur suicide assistance from family members or friends, subjects patients to numerous risks. Complications may take place during the assisted suicide. For example, a patient may have difficulties taking a medication or may experience a sudden unexpected reaction to the medication taken. Further, depression will also go undetected and unaddressed, as the ban on healthcare professionals in the DPP's Policy includes psychiatrists and psychologists.

Those who are unable to obtain the assistance of family members or friends in England and Wales are left only with the option (provided they are financially able) of seeking help from right-to-die organisations abroad. Some may seek an assisted suicide sooner than otherwise, because of the need to travel abroad whilst they are physically able to do so. However, those going to Dignitas to end their lives may be at risk under the Swiss legal framework for assisted suicide. As was noted in Chapter Five, Swiss law is similarly vague. To-date, Swiss courts have only affirmed that physicians are permitted to assist in suicides for conditions indisputably leading to death.[81] Yet, Britons who have been assisted to die at Dignitas have suffered from various conditions, inclusive of non-terminal and curable medical conditions.[82] There is also no requirement for a mental health evaluation under Swiss law.[83] Thus, right-to-die organisations may fail to detect depression or any other mental disorder that impairs the decision-making capacity of patients. Further, as the volunteers at such organisations are not medically trained, they will not be able to address the complications that can arise after the lethal medication is ingested.[84] Such complications occurred in the 2010 case of Andrew Colgan, who due to his high tolerance to medication, remained alive for more than 90 minutes after ingesting lethal medication.[85]

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[80] See section 5.5.

[81] Zurich Case (ch5 n281).

[82] See text to ch5 nn284-286.

[83] See text to ch5 n289.

[84] See text to ch5 nn305-306.

[85] J Fielding and V Scullard, 'Our mother cuddled him but Dignitas told her to stop' *The Express* (London,26 June 2011).

Research Question iii)

Can a person's 'quality of life' determine whether they should have an assisted death?

As observed in Chapter Four, individuals seeking to end their lives at right-to-die organisations abroad are already doing so based on a personal assessment of their poor quality of life due to illness, disease or disability. It was appreciated that terminally ill patients who have a higher quality of life – in terms of physical, cognitive and social functioning – are less likely to desire a hastened death.[86] The 'best interests' assessment under common law (prior to the MCA 2005) for cases involving the withdrawal or withholding of life-sustaining treatment from incompetent patients, had in effect been a paternalistic 'quality of life' judgement by the courts and physicians. As of 2007, the law under the MCA provides that in cases where life-sustaining treatment is futile or overly burdensome to an incompetent patient, or where there is no prospect of recovery with such treatment, it may be withdrawn or withheld in the 'best interests' of the patient. As noted above, the 'best interests' assessment under the MCA 2005 takes into account the previous statements by a patient about their wishes and feelings about life-sustaining treatment. By referring to a patient's subjective views, the 'best interests' assessment effectively focuses on a subjective evaluation of quality of life. Thus, where possible, there is now respect for patient autonomy, and the English courts and physicians are deterred from exercising a paternalistic quality of life judgement. As mentioned above, the *Aintree NHS Trust* case[87] confirmed that the 'best interests' assessment under the MCA 2005 requires a patient's subjective interests to be considered. It has been accepted in this thesis that for consistency with the law on the withdrawal and withholding of life-sustaining treatment from incompetent patients, a subjective assessment of 'quality of life' should also be the basis for any right conferred upon a competent terminally ill patient to request a physician-assisted suicide.

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[86] Price (ch1 n45).

[87] *Aintree NHS Trust* case (ch2 n306).

Research Question iv)

Would a law permitting assisted death for a restricted group of people lead to assisted death being practised beyond that group?

As demonstrated in Chapter Six, there is evidence to support the ‘slippery slope’ argument in relation to assisted death from the Netherlands, Belgium, and Oregon. The evidence demonstrates that the laws have been extended to a wider group of people beyond that originally intended.

In respect of the Netherlands,[88] prior to the Dutch Act, there is evidence to support both the ‘logical’ and ‘empirical’ slippery slope arguments. In support of the ‘logical’ argument, the scope of ‘unbearable suffering’ was extended over time, whilst in support of the ‘empirical’ argument, the Dutch courts disregarded breaches of the KNMG guidelines when considering each case based on its own circumstances. The expansion of lawful assisted death since the Dutch Act came into force also supports the ‘logical’ slippery slope argument. The Dutch Act has extended the law to a wider group of people including minors aged between 12 and 16 years. Since 2004, the RRCs have allowed those with the early onset of dementia to make a lawful request for assisted death, on the basis that the prospect of a further loss of dignity constitutes ‘unbearable and hopeless suffering’. The Dutch Act also recognises the advance declarations for assisted death of incompetent patients, including for reasons of dementia and Alzheimer’s disease. Further support for the ‘logical’ argument is provided by the 2005 *Groningen Protocol*, which made neonatal termination lawful. By endorsing the *Groningen Protocol*, the Dutch authorities have accepted the practice of non-voluntary euthanasia for infants.

In respect of Belgium,[89] it has been found in this thesis that there is support for both the ‘logical’ and ‘empirical’ slippery slope argument. In support of the ‘logical’ argument, the Belgian CFCE[90] has extended the legal boundaries of lawful euthanasia to those suffering from a mere anticipation of future coma, loss of independence, or progressive dementia. In support of the ‘empirical’ argument, there was evidence of regular contraventions of the Belgian Act by physicians, and a lack of enforcement by Belgian authorities. Such contraventions include euthanasia being carried out by nurses and

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[88] See section 6.3.

[89] See section 6.4.

[90] CFCE (ch5 n162).

LEIF physicians.[91] Evidence of widespread non-voluntary euthanasia has been found in Belgium. However, there is no evidence that this has increased since the Belgian Act legalised voluntary euthanasia.

In Oregon,[92] no evidence of an actual slippage was found in relation to physician-assisted suicide. However, several slippery slope mechanisms were found which each increase the risk of an ‘empirical’ slippage. These are physician-shopping, referrals by suicide advocacy groups, the fact that mental health evaluations are not compulsory under the DDA, and the difficulties of obtaining an accurate prognosis when attempting to estimate a six-month life-expectancy.

In England and Wales, no evidence of an actual slippage was found in relation to the law concerning withdrawal and withholding of life-sustaining treatment from incompetent patients in a PVS.[93] However, several slippery slope mechanisms were found which increase the risk of both a ‘logical’ and ‘empirical’ slippage. In relation to a ‘logical’ slippage, two mechanisms stem from the 1999 BMA guidance. The first is the extension of the withdrawal and withholding of life-sustaining treatment from patients in a PVS to patients with ‘other serious conditions’, such as those with severe dementia or those who have suffered a serious stroke, and the second is an assertion that not all end-of-life medical decisions require review by a court.[94] In relation to an ‘empirical’ slippage, these mechanisms are the reliance by courts on expert testimony on the awareness of each individual patient rather than reliance on a pre-defined set of clinical criteria, and the fact that medical opinion as to what constitutes a PVS is still developing.

It has been accepted in this thesis that the experience from the Netherlands and Belgium shows that assisted death laws which are not effectively regulated and enforced can lead to a risk of vulnerable people being abused. These experiences provide a basis for proceeding with caution in developing law reform for England and Wales. They highlight the need for safeguards. Barriers on the slope and mechanisms by which slippages down the slope can be detected and, thereafter, rectified are essential.[95] With

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[91] LEIF (ch5 n190).

[92] See section 6.5.

[93] See section 6.6.

[94] See BMA, *Withholding and Withdrawing Life-prolonging Treatment* (ch4 n76) [21.4].

[95] Downie (ch6 n174) 119.

this in mind, such a proposal for law reform will be addressed under the following and final research question.

Research Question v)

If the law on assisted death is to be reformed in England and Wales, what would the scope of the change be and how should the proposal for law reform be drafted?

The law reforms proposed in this thesis only apply to competent adult patients. Thus, the following proposal for England and Wales does not address patients such as incurably ill and severely disabled neonates, minors, and patients with dementia. It also does not include the recognition of advance directives of competent patients.

The law reforms proposed include some features from past law reform proposals. Incremental changes have been made to these features to develop them into effective safeguards to prevent abuse of the law and protect the vulnerable in society. It is proposed that physician-assisted suicide should be made available as a medical option of last resort to competent patients who are terminally ill and suffering unbearably and experiencing a poor and unacceptable quality of life due to their illness. Listed below are 14 key provisions that will need to be included in the proposed law, to reduce the risk of a slide down a slippery slope, and to also detect and address any such slippages should they occur.

(i) Physician-assisted suicide will be made available as a medical option of last resort to terminally ill patients.

Chapter Two demonstrated that society’s needs would be better served if physicians were involved in assisted suicides.[96] Physicians have the required competence to achieve a safe and humane death, thus reducing the risk of failed assisted suicides and giving patients the comfort of professional medical assistance in the event that any complications arise when the patient takes the lethal medication. As with the Dutch law on assisted death, physicians should stay with the patient continuously from the time the patient takes the lethal medication until the patient’s death.[97]

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[96] See section 2.2.3 under *Healthcare professionals*.

[97] Griffiths (ch5 n30) 106. See also ch5 nn69-74.

As has been established in this thesis, by restricting lawful physician-assisted suicide to terminally ill patients, the proposed law reform would be in line with current public opinion in England and Wales. The notion of lawful euthanasia by physicians is rejected in this thesis. Such a law would be open to medical paternalism, as the patient would not have control over the final act that causes their death. As asserted by the House of Lords' Select Committee on the ADTI Bill 2004 ('2004 Select Committee'), the key issue with assisted death is that the responsibility for the ultimate act should rest with the patient. This has the effect of making patients think more carefully before carrying out the act to end their lives.[98] As noted in Chapter Two, the 2004 Select Committee also found that the experiences of the Netherlands and Oregon suggest a strong connection between the inclusion of euthanasia in a law on assisted death, and a significantly higher rate of deaths.[99] This is supported by the 2012 OPHD annual report which indicates that approximately one third of patients do not use the lethal medication once prescribed.[100] They rather treat it as an 'insurance policy'.[101]

The proposal is for a law which permits physician-assisted suicide that focuses on a patient's terminal illness and its treatment. As physician-assisted suicide would be available as a medical option, the proposed law will not address any suffering that is unrelated to a terminal illness e.g. 'tired of life', 'prolonged dwindling', and existential suffering. As concluded in Chapter Four, these examples of other types of suffering are not within a physician's professional competence.[102]

(ii) There must be a voluntary verbal request for physician-assisted suicide by a competent patient to their attending physician, with whom they have an established continuing relationship. The attending physician and independent consulting physician will have to be certain that the patient is competent and has made a voluntary, informed and settled decision free of undue influence. A mental health evaluation will also have to be carried out to ensure that the patient is not suffering from any mental disorders that could impair his or her decision-making capacity. The patient may revoke the request for physician-assisted suicide at any time and in any manner.

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[98] See section 2.4.2.

[99] See text to ch2 nn371-372.

[100] See text to ch5 n547.

[101] Ganzini and Dahl (ch5 n548).

[102] See text to ch4 nn151-152.

As demonstrated in Chapter Three, the requirement for an established physician-patient relationship could help ensure that the patient's decision is autonomous, voluntary and well-considered.[103] The physician who has a treatment history with the patient would not only be better able to determine that their patient is not under pressure or coerced to end their life, but would also have better knowledge of their patient's medical history. The requirement for a physician-patient relationship is based on the benefits realised through the '*huisartsen*' (family-care physicians) which often administer the Dutch law on assisted death.[104] This proposed requirement would be able to address the phenomenon of 'physician-shopping' which is a criticism of Lord Falconer's AD Bill 2013.[105] As demonstrated by the experiences with Oregon's DDA[106] and the ROTI Act[107] in the Northern Territory of Australia, patients have been able to approach more accommodating physicians via 'physician-shopping'.

Based on the ROTI Act, to ensure that the patient's decision is a well-considered autonomous decision, the attending physician and consulting physician will have to be satisfied that the patient has considered the implications of their decision, has been informed of the prognosis expected, and has understood the treatment options that are reasonably available, including palliative care.[108] Similar requirements have been included in Lord's Joffe's ADTI Bill 2004[109] and the AD Bill 2013[110].

(iii) The patient will have to follow up with a written request for physician-assisted suicide at least 12 days after the verbal request. If the patient has a prognosis of less than a month to live, then the written request may be made at least six days after the initial verbal request. The written request must be made in the presence of the attending physician, the consulting physician, and two witnesses. At least one witness must not be a relative, the patient's beneficiary, or a person directly involved in the patient's care or treatment.

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[103] See text to ch3 nn200-203.

[104] See Lindemann and Verkerk (ch5 n73), and text to ch5 n73. See also section 5.2.2.

[105] See section 2.4.6.

[106] See section 5.7.2.

[107] See section 5.6.2.

[108] ROTI Amendment Act (ch5 n383) sub-s7(1)(e).

[109] ADTI Bill 2004 (ch1 n48) cl 2.

[110] AD Bill 2013 (ch1 n57) cl 3.

This proposed requirement helps ensure that the patient is not feeling pressure from others to follow through with the earlier verbal request. Based on the DDA, to protect vulnerable patients and ensure that they are making an autonomous request, at least one witness will have to be completely independent.[111] Additionally, the joint presence of the attending physician and consulting physician, which is based on the ROTI Act,[112] increases the assurance that the patient's request is voluntary and that they are not coerced or influenced by third parties. Both the ADTI Bill 2004 and the AD Bill 2013 included a requirement for witnesses. The former required two witnesses, one a solicitor and the other a person known to the patient,[113] while the latter required only one witness who was not related or involved in the patient's treatment or care.[114]

(iv) The patient must be suffering from a terminal illness. Terminal illness must be defined as an incurable and irreversible disease that has been medically confirmed and will within reasonable medical judgement produce death within six months. The attending physician and the consulting physician will have to independently assess the patient to confirm that the patient has a terminal illness with a prognosis of six months or less to live.

The definition of terminal illness is based on the DDA.[115] However, as demonstrated in Chapters Two[116] and Five[117], an accurate prognosis in terms of life-expectancy is not possible for a terminal illness. This was evidenced by the OPHD annual reports in Oregon, where patients who opted to defer the use of their prescription had frequently lived longer than six months.[118] The limitations on prognosis were also demonstrated by the limited cases under the ROTI Act,[119] and noted by the 2004 Select Committee[120]. Although it has been accepted in this thesis that there are practical limitations on the accuracy of prognoses, this proposed requirement is included to avoid any potential abuse of the law. As with the DDA, the difficulties in accurate prognosis are taken into

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[111] Or Rev Stat §127.810.

[112] ROTI Amendment Act (ch5 n383) sub-ss7(1)(i)-(k).

[113] ADTI Bill 2004 (ch1 n48) cl 4.

[114] AD Bill 2013 (ch1 n57) cl 3.

[115] Or Rev Stat §127.800 (1998).

[116] See text to ch2 nn382-386.

[117] See text to ch5 nn476-483.

[118] Battin (ch5 n480). See text to ch5 nn481-482.

[119] See text to ch5 nn395-398.

[120] See text to ch2 nn382-386.

account by the inclusion of the words ‘within reasonable medical judgement’. If the consulting physician’s prognosis differs from that of the attending physician, the patient will be referred to a body of informed medical professionals[121] (within the NHS) for a confirmation on prognosis that is ‘within reasonable medical judgement’. This proposed requirement takes into account the recommendations of the 2004 Select Committee that the definition for terminal illness must reflect the realities of clinical practice as regards accurate prognosis.[122] The prognosis of six months is similar to the provision in the AD Bill 2013.[123]

(v) The patient must be suffering unbearably and experiencing a poor and unacceptable quality of life due to the terminal illness. The attending physician will have to make sure that a quality of life assessment is carried out within 12 days of the patient’s verbal request.

It is proposed that physician-assisted suicide should be made available to terminally ill patients experiencing a poor and unacceptable quality of life. The quality of life assessment will be based on a subjective patient evaluation. As the proposed law will be available as a medical option of last resort, the assessment of quality of life will be restricted to the pain and suffering (physical or psychological) medically caused by the patient’s terminal illness and its related treatment. Although it may be difficult for terminally ill patients to complete subjective measurement instruments due to ill health or a fragile state,[124] for the purposes of this law reform, third party assessments will not be accepted.[125] As the proposed law is based on patient autonomy, and suffering is a subjective experience which cannot be assessed objectively by clinical methods or reliably be attributed to the underlying condition,[126] quality of life must be determined by a subjective patient evaluation.

In drafting this provision, the option of requiring that the suffering be ‘unrelievable’, rather than ‘unbearable’ was considered. As noted in Chapter Two, ‘unrelievable’ was the term favoured by the 2004 Select Committee when it considered the ADTI Bill

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[121] *Bolam* test (ch4 n18).

[122] 2004 HL Select Committee Report Vol I (ch1 n49) para 269(c)(iii).

[123] AD Bill 2013 (ch1 n57) cl 3, and sch for form of declaration pursuant to cl 3.

[124] Cohen (ch4 n169), Thompson (ch4 n170).

[125] See section 4.5.

[126] 2004 HL Select Committee Report Vol I (ch1 n49) paras 127-130.

2004.[127] The term was favoured for its greater objectivity, and as a means of compelling patients to experience palliative care first. In the proposed law reform in this thesis (Provision (ix) below), however, the physician is required to ensure that palliative care is exhausted first.

(vi) The attending physician must (a) inform the patient of the medical diagnosis, prognosis, alternative treatment options available, including palliative care, and of the patient's right to revoke his request at any time; (b) be satisfied that the patient's request is made voluntarily, and that the patient has made an informed decision; (c) refer the patient to an independent consulting physician for a second opinion; (d) refer the patient to a psychiatrist or psychologist for a mental health evaluation; and (e) be satisfied that a patient is suffering unbearably from a terminal illness, and that the suffering is affecting their quality of life.

(vii) The attending physician will have to refer the patient to an independent consulting physician, who must be a specialist in the patient's terminal illness. For this purpose, a network of specialists in various terminal illnesses must be provided by the NHS. These specialists must be prepared to act as independent consulting physicians under the proposed law. The consulting physician will have to (a) confirm the diagnosis and prognosis by the attending physician; and (b) be satisfied that the patient has a clear and settled intention to end their own life which has been reached voluntarily, on an informed basis and without coercion or duress. When the consulting physician's opinion differs from the attending physician's prognosis, the patient's medical condition will have to be confirmed by applying a professional medical judgement in accordance with a responsible body of informed medical opinion[128] from the NHS.

By requiring consulting physicians to act independently of attending physicians, this would prevent friends or colleagues of the attending physician from providing the required medical confirmation to facilitate the proposed law. This was the experience with the Dutch law prior to the Dutch Act.[129] However, pursuant to the Dutch Act, the

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[127] See text to ch2 n389.

[128] *Bolam* test (ch4 n18).

[129] See text to ch5 nn66-67.

SCEN[130] programme provides suitably trained physicians to act as independent consulting physicians in the Netherlands, as does the LEIF[131] network in Belgium[132]. Based on the ROTI Act,[133] an independent second opinion from an expert on the patient's terminal illness provides greater assurance of the diagnosis and prognosis of the patient's terminal illness. A network of specialists provided by the NHS to act as independent consulting physicians discourages 'physician-shopping'. As with the ROTI Act, the DDA did not specify how differing opinions on a patient's prognosis were to be addressed. This failure encourages physicians and patients to obtain the desired confirmation on prognosis by 'physician-shopping'.[134] The ADTI Bill 2004[135] and AD Bill 2013[136] both included similar provisions, requiring a consulting physician to have either qualifications, experience, or a specialisation in the patient's terminal illness.

(viii) Soon after the medical examination by the consulting physician, the attending physician will have to refer the patient to a psychiatrist or psychologist for a mental health evaluation. For this purpose, a network of psychiatrists and psychologists must be provided by the NHS. Members of this network must be prepared to carry out the required mental health evaluations under the proposed law. They will have to determine that (a) the patient's decision is not distorted by treatable clinical depression; and (b) the patient is not suffering from any other psychiatric or psychological disorder causing impaired judgement. The mental health evaluation will have to be performed twice. The first evaluation must be within 12 days of the patient's verbal request, and the second evaluation must be a day before the lethal medication is given to the patient. In cases where the patient has a prognosis of less than a month to live, then the first evaluation must be within six days of the patient's verbal request, and the second evaluation must be on the day the written request is made.

This mandatory requirement for a mental health evaluation addresses the concern in the ADTI Bill 2004 which proposed that only if a physician believed that the patient was

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[130] SCEN (ch5 n68).

[131] LEIF (ch5 n189).

[132] See text to ch5 n191.

[133] See section 5.6.2.

[134] See Kissane (ch5 n395), and text to ch5 n500.

[135] ADTI Bill 2004 (ch1 n48) cl 2.

[136] AD Bill 2013 (ch1 n57) cl 3.

not competent, were they to refer the patient to a psychiatrist.[137] Similarly, the DDA only requires the attending physician or consulting physician to refer the patient for a mental health evaluation if they believe that the patient's judgement is impaired by depression or some other psychiatric or psychological disorder.[138] However, as established in Chapter Three, depression amongst terminally ill patients is significantly overlooked and under-treated in England and Wales.[139] Experiences with the DDA also confirm that physicians often fail to recognise depression. This is evidenced by the downward trend in the percentage of patients being referred for formal psychiatric or psychological evaluation.[140] Thus, it is not sufficient to merely rely on the professional competencies of physicians when screening for depression.[141] A network of psychiatrists and psychologists provided by the NHS would discourage 'physician-shopping' for a favourable evaluation. As observed in Chapter Five, this often takes place in Oregon to obtain the desired mental health evaluation.[142] Nevertheless, it is also accepted that a mental health evaluation is not foolproof. Despite having depression at the time of a mental health evaluation, some terminally ill patients in Oregon were still cleared for an assisted suicide under the DDA.[143] Based on the ROTI Act, it was noted that patients may not be cooperative or volunteer information during a mental health evaluation for fear of frustrating their chances of getting an assisted death under the law.[144]

As observed in Chapter Five, in the absence of a long-term relationship with a patient, only a small number of psychiatrists are confident that they can satisfactorily determine in a single visit whether a patient is legally competent to commit suicide.[145] Thus, under the proposed law reform, a mental health evaluation will have to be performed by the same psychiatrist (or psychologist) at two different times, once before the written request for physician-assisted suicide is made, and once after the written request. The second mental health evaluation performed a day before the lethal prescription is taken would ensure that a patient's capacity is assessed at an appropriate point before their suicide. This would substantially address the concern with the AD Bill 2013, that

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[137] ADTI Bill 2004 (ch1 n48) cl 8.

[138] Or Rev Stat §127.800 (1998).

[139] See text to ch3 nn292-297.

[140] See text to ch5 nn501-509.

[141] Battin (ch5 n513).

[142] See text to ch5 nn519-522.

[143] See text to ch5 n514.

[144] See text to ch5 nn401-402.

[145] See text to ch5 nn516-517.

mental capacity may be lost in the period between the request being approved and the drugs being supplied and swallowed.[146] A mental health evaluation performed a day before the assistance may not satisfy the requirement under the MCA 2005 for an assessment of a person's capacity to be based on their ability to make a specific decision at the time it needs to be made.[147] However, it may not be practical to have a mental health evaluation on the same day of the assisted suicide. A patient may be too fragile or weak for a psychiatric consultation immediately before taking the lethal medication. It would be reasonable to regard a mental health evaluation performed a day before the assisted suicide to be a decision that is most current. Instances of a second mental health evaluation carried out on the same day of the assisted suicide should be restricted to situations where a patient has a prognosis of less than a month to live.

(ix) The attending physician must ensure that palliative care treatment is explored and exhausted by a palliative care specialist before physician-assisted suicide is resorted to by the attending physician as a medical option of last resort. The attending physician must refer the patient to a palliative care specialist immediately after the consulting physician has confirmed the patient's diagnosis and prognosis. A network of palliative care specialists for purposes of the proposed law must be provided by the NHS. Physician-assisted suicide will not be proceeded with if a palliative care specialist believes that there are palliative care options reasonably available to alleviate a patient's pain and suffering to levels acceptable to the patient. Until the patient experiences palliative treatment as recommended by the palliative care specialist, they will not be eligible for physician-assisted suicide.

The proposed law reform has expanded on a similar provision in the ADTI Bill 2004 and the AD Bill 2013. The former merely required a palliative care specialist to have discussed the option of palliative care with the patient,[148] and the latter merely required the patient to be informed of the available palliative, hospice and other care options.[149] The proposed requirement implements the recommendations of the 2004 Select Committee that patients should actually experience palliative care rather than merely be informed of it as an option.[150] As noted in Chapter Five, Caritas Flanders believed that a

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[146] Camden-Smith (ch2 n444) para26.

[147] MCA, Code of Practice paras 4.36 and 4.4.

[148] ADTI Bill 2004 (ch1 n48) cl 3.

[149] AD Bill 2013 (ch1 n57) cl 3.

[150] 2004 HL Select Committee Report Vol I (ch1 n49) para269(c)(vi).

similar requirement in the Belgian Act – for physicians to merely discuss palliative treatment with patients – was insufficient.[151] Caritas appreciated that not all physicians were familiar with palliative care options, and so imposed a mandatory consultation with a palliative care expert on all terminally ill patients.[152]

Based on the ROTI Act,[153] the proposed law will only be available to those whose pain and suffering cannot be alleviated to levels acceptable to them. It restricts the availability of physician-assisted suicide to those who are unable to find any relief for their pain and suffering. This proposed requirement addresses a concern with the Dutch law where assisted death is often resorted to as an alternative to palliative care.[154] As discussed in Chapter Five, Dutch doctors have performed euthanasia on patients who refused palliative care treatment that may have alleviated their pain and suffering.[155] In doing so, it cannot be said that assisted death is being regarded as a medical option of last resort under the Dutch legal framework.[156]

(x) Physician-assisted suicide will have to take place within 30 days of the initial verbal request. There must at least be a 12-day lapse between the patient’s initial verbal request and the follow-up written request, and at least a further two-day lapse from the time of the patient’s written request to the time the lethal medication is given to the patient to be ingested. In cases where the patient has a prognosis of less than a month to live, there must at least be a six-day lapse between the patient’s initial verbal request and the follow-up written request, and the lethal medication must be given to the patient to be ingested on the same day the written request is made.

The rationale for a 30-day period is to ensure timely relief for those patients who are truly suffering unbearably. However, as noted in Chapter Three, the desire for death often changes as personal circumstances change.[157] Thus, the proposal for the assisted suicide to take place anytime within 30 days of the initial verbal request takes into account the possibility for change in the patient’s circumstances within this time period. As discussed in Chapter Four, a patient may adapt to their pain and suffering and find

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[151] Gastmans (ch5 n227).

[152] See text to ch5 nn225-228.

[153] ROTI Amendment Act (ch5 n383) sub-s8(1).

[154] Keown (ch5 n88).

[155] See text to ch5 nn85,89 .

[156] See text to ch5 nn83-88.

[157] See text to ch3 nn223-224.

their quality of life bearable.[158] Based on the DDA[159] and the ROTI Act[160], the requirement for the ‘cooling off’ periods protects vulnerable patients. The ‘cooling off’ periods provide an opportunity for patients to reconsider their request for assisted suicide, and deters them from making hasty decisions. They provide an assurance of the persistence and certainty of the patient’s request. The ‘cooling off’ periods in the proposed law are regarded as a reasonable compromise to look after the needs of those determined to put an end to their suffering as soon as possible and those who need a period of reflection and contemplation.

As noted in Chapter Two, there is a better chance at an accurate prognosis when a patient is within the last two or three weeks of their life.[161] On this basis, if a patient has a prognosis of less than a month to live, the proposal is for a much shorter ‘cooling off’ period between the verbal and written requests, and for the lethal medication to be given to the patient to be ingested on the same day of the written request, soon after a second mental health evaluation is performed. This requirement takes into consideration the recommendation of the 2004 Select Committee that any future Bill should balance the need to avoid increased suffering for determined applicants against the desirability of providing time for reflection for the less resolute.[162] The provision in the AD Bill 2013 has a two week waiting period before patients get to request for the drugs, which is shortened to six days if death is to be expected within one month.[163]

(xi) A patient will have to confirm their request for assisted suicide immediately before taking the lethal medication. If a confirmation of request cannot be obtained for whatever reason, the attending physician must not proceed with the assisted suicide. If a confirmation has been obtained, the attending physician will have to give the patient the lethal medication to be ingested. The patient must take the lethal medication in the presence of the attending physician and the consulting physician, both of whom must remain with the patient until the patient dies. If a patient is physically unable to take the lethal medication, or if they change their mind and do not wish to take it, the lethal medication will have to be returned to the attending physician. Under such circumstances, the assisted suicide will not take place.

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[158] See text to ch4 nn136-138.

[159] Or Rev Stat §127.850.

[160] ROTI Amendment Act (ch5 n383) sub-ss7(1)(i)-(k),(n)-(p).

[161] 2004 HL Select Committee Report Vol I (ch1 n49) para118.

[162] ibid para269.

[163] AD Bill 2013 (ch1 n57) cl 4.

A confirmation of request immediately before taking the lethal medication would provide further assurance of a patient's autonomous decision to die, and that their desire for death has not changed. As there was no similar requirement under the ROTI Act, there remained potential uncertainty as to whether euthanasia had been performed based on a patient's voluntary autonomous request to die.[164] Under the proposed law reform, the lethal medication is only given to a patient when they are to take it. This avoids the potential for abuse and misuse of medication which currently exists in Oregon.[165] Under the DDA, although there is a confirmation of request immediately before the prescription for lethal medication is written,[166] patients are allowed to collect their medication weeks or months before they actually ingest them.

The presence of the attending physician and consulting physician when the patient takes the medication will ensure that there is professional medical assistance available in the event of any complications during or after the ingestion. After the medication is ingested, if the physicians determine that the suicide is likely to be unsuccessful due to complications, then under their general duty of care, the objective would become one of restoring the patient to their previous state of health.

The presence of the physicians also protects vulnerable patients from any undue influence, pressure, or duress from others immediately before the ingestion, and ensures that the lethal medication is not misused in any way. The AD Bill 2013 also proposes for an assisting healthcare professional to be with the patient when the medication is ingested, and to remain with them until they die.[167] The Bill further states that a physician need not be in the same room, but may instead be within close proximity to the patient. However, as the proposed law regards physician-assisted suicide as a medical procedure, the proposed provision requires that ingestion occur in the presence of a physician.

The ADTI Bill 2004 proposed that the attending physician be permitted to end a patient's life by administering euthanasia, when the patient is physically unable to

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[164] See text to ch5 n413.

[165] See text to ch5 nn535-537.

[166] Or Rev Stat §127.830.

[167] AD Bill 2013 (ch1 n57) cl 4.

ingest lethal medication.[168] No such option of euthanasia is proposed in this thesis for the reasons noted under Provision (i), above.

(xii) Following the patient's death, the attending physician and consulting physician overseeing the death will have to certify the patient's death as 'assisted suicide'. The attending physician will have to report the death to a Monitoring Commission responsible for regulating the practice of the law. The medical reports of the attending physician, consulting physician, psychiatrist or psychologist, and palliative care specialist will have to be filed in the patient's medical records and sent to the Monitoring Commission within seven days of the assisted suicide. The Monitoring Commission, which will be under the charge of the Chief Medical Officer for England and Wales, will collect and publish national data on reported cases of physician-assisted suicide, and publish an annual report for Parliament each year. Findings from these reports could assist Parliament to conduct a full review of the law's implementation. The attending physician will also keep a record of requests for physician-assisted suicide that fail to meet the requirements under the law. This record will be sent to the Monitoring Commission bi-annually.

The reporting requirements under the proposed law must be strictly enforced to ensure there is no abuse of the law. This will not only address the issue of fabrication of reports or under-reporting in the Netherlands,[169] Belgium,[170] and Oregon,[171] but would also avoid the potential for a 'slippery slope' caused by a disregard for the law and lack of enforcement such as that experienced in Belgium.[172] To ensure a high quality of reports nationwide, it is recommended that a similar accreditation and training programme be implemented for consulting physicians, as was established in the Netherlands and Belgium for the SCEN and LEIF consulting physicians.[173]

As in the Netherlands[174] and Belgium[175], the Monitoring Commission must investigate cases of suspected non-compliance retrospectively, and refer instances of malpractice to

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[168] ADTI Bill 2004 (ch1 n48) cl 1(2).

[169] See text to ch5 nn99-100.

[170] See text to ch5 n218.

[171] See text to ch5 nn466-467.

[172] See section 6.4.

[173] See text to ch5 nn68,192.

[174] See text to ch5 n79.

[175] See text to ch5 n210.

the professional bodies or prosecutorial authorities where appropriate. As with the Dutch RRCs and the Belgian CFCE, the Monitoring Commission would encourage reporting, by providing a buffer between physicians and the prosecuting authorities.[176]

Society's needs for transparency will be met by the statistics reported by the Monitoring Commission in its annual reports. There will also be adequate oversight of procedures under the proposed law, as unlike the law in Oregon,[177] physicians' reports will not be merely compiled but will also be reviewed. As data will also be collected on requests that are declined under the proposed law, the Monitoring Commission would be able to include such data in their reports and better guard against physician-shopping.

The Commission would have protocols which encourage physician interviews, including the reasons why patients are refused physician-assisted suicide. Not only would this requirement ensure public accountability of the practice of physician-assisted suicide but also provide greater transparency in the law.[178] As noted in Chapter Five, a shortcoming of the OPHD was that it performed a minimalist monitoring function, with no focus on identifying abuse.[179] The requirement for a Monitoring Commission and for the Chief Medical Officer to be responsible for monitoring the operation of the proposed law are combined features taken from the ADTI Bill 2004[180] and the AD Bill 2013[181]. As a further safeguard to detect abuse, it is recommended that the government commission periodic nationwide surveys similar to those of the Netherlands.[182]

(xiii) No physician shall be under a duty to participate under this law if they have a conscientious objection.

This legal requirement has taken into account the 2004 Select Committee's recommendation that any new Bill should not place on a physician with conscientious objection the duty to refer a patient requesting physician-assisted suicide to another

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[176] van der Wal (ch5 n95) 1710.

[177] See text to ch5 n466.

[178] Hiscox (ch5 n474).

[179] See text to ch5 n469.

[180] ADTI Bill 2004 (ch1 n48) cl 14.

[181] AD Bill 2013 (ch1 n57) cl 9.

[182] The Remmelink Survey (ch5 n85), The van der Maas Survey (ch5 n92-2), and the Onwuteaka-Philipsen Survey (ch5 n92-3).

physician without such objection.[183] This provision is similar to the provision in the AD Bill 2013.[184]

(xiv) A person who acts according to the law on physician-assisted suicide will not be guilty of any offence.

This requirement also appeared in the ADTI Bill 2004[185] and the AD Bill 2013[186]. As explained in Chapter Five, with reference to a similar requirement in the ROTI Act,[187] this provision addresses the fear by physicians of criminal prosecution.

Finally, it is intended that the proposed law reform will address the controversies in the debate on the legalisation of assisted death in England and Wales. In line with the recommendations of the 2004 Select Committee,[188] and the House of Lords' decision in *Purdy*,[189] the proposed law on physician-assisted suicide is aimed at addressing the needs of society, particularly the terminally ill. The law is based on autonomy and self-determination. The proposal takes into account the failings of the DPP's Policy in respect of making suicide assistance an activity carried out by non-medically trained people, thereby subjecting patients to the risk of further harm as a result of failed suicides and medical complications. Rather than abandon their terminally ill patients (with whom they already have an established physician-patient relationship), it would be more ethical for physicians to provide a medical option of last resort in the form of assisted suicide to those suffering unbearably and experiencing an unacceptable quality of life. Quality of life, based on a subjective assessment, would be consistent with the current focus on a subjective evaluation of quality of life in medical decisions involving the withholding or withdrawal of life-sustaining treatment from incompetent patients. To protect the vulnerable in society, the proposed law reform includes referrals to an independent consulting physician, a psychiatrist or psychologist, and a palliative care specialist. Cooling off periods have also been included to enable the attending physician to be certain of the patient's autonomous and voluntary request for assisted suicide. In line with patient autonomy, a patient is responsible for the final act that leads to the

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[183] 2004 HL Select Committee Report Vol I (ch1 n49).

[184] AD Bill 2013 (ch1 n57) cl 5.

[185] ADTI Bill 2004 (ch1 n48) cl 10.

[186] AD Bill 2013 (ch1 n57) cl 6.

[187] See text to ch5 n419.

[188] 2004 HL Select Committee Report Vols I, II and III (ch1 n58).

[189] *Purdy* (HL)(ch1 n31).

death under the proposed law. The safeguards will have to be rigorously enforced to prevent potential abuse, and to protect the vulnerable.

The 14 proposed legal provisions aim to provide barriers on a ‘slippery slope’ and mechanisms by which slippages down the slope can be detected and addressed. While it is never possible to completely guarantee that abuse and unjustified practices will not take place, strong and effective safeguards, may reasonably meet the concerns of those presently opposed to the legalisation of assisted death in England and Wales. With such safeguards and under the prescribed circumstances, these provisions enable the autonomous decision of a competent adult who wishes to end their life with the comfort of assistance from a physician.

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