Report

The Meaning of Dignity:
What's Beneath the Assisted Dying Debate?

Andrew Grey

Foreword by Nick Spencer

Theos is the UK's leading religion and society think tank. It has a broad Christian basis and exists to enrich the conversation about the role of faith in society through research, events, and media commentary.

theosthinktank.co.uk

Published by Theos in 2024

ISBN: 978-0-56-403903-6

All visual images are taken the Theos animation Dying for Beginners by Emily Ikoshi

Theos Licence Department
77 Great Peter Street
London SW1P 2EZ

+44 (0) 20 7828 7777
hello@theosthinktank.co.uk
theosthinktank.co.uk

Report

The Meaning of Dignity:

What’s Beneath the Assisted Dying Debate?

Andrew Grey

Foreword by Nick Spencer

This report in 60 seconds

1. The topic of assisted dying touches on our deepest beliefs and convictions, in particular, our **idea of dignity**. Everyone wants to honour and respect human dignity at the end of life. The problem is that concept has radically different meanings.
2. One approach argues that **dignity lies in autonomy**. We should have the right to end our lives at our choosing, especially if we are in pain or facing imminent death.
3. The other approach says **dignity lies in relationships**, and is about being appreciated, valued and loved. It believes that the best way to honour people's dignity is to care for them.
4. We believe that if society were to place its weight behind dignity-as-autonomy and so grant the right to die to those who choose it, **even if that right is at first tightly restricted to the terminally ill**, we would **no longer have a cogent reason to deny it to people who wanted to end their lives** but who were not terminally ill or even in physical pain.
5. However much we might insist on practical or legal brakes (e.g. legal restrictions) to stop us sliding down the slippery slope, if we locate human dignity in ability to choose, we will no longer have any principled or ethical brakes – **no deep reason to deny people their choice to die in other circumstances**.
6. This is **what has happened in numerous jurisdictions** that have legalised assisted dying over the last 20 years.
7. Instead, we argue that the best way fully to honour someone's dignity is to recognise and respect their life in relationship and **to love, value and care for them** as long as it is possible.

Contents

Foreword

In 2018, Theos published a report exploring the idea of dignity in the assisted dying debate. This was, at the time, a slightly 'theoretical' piece, in the sense that parliament had voted against legalising assisted dying three years earlier and, although the topic remained a constant source of interest for some back benchers, there was little immediate prospect of it returning to parliament.

That changed, remarkably rapidly, in the autumn of 2024, when a private members' bill to legalise the practice came high up in the ballot, and the new Labour Prime Minister, Keir Starmer, made a personal promise to the TV star Esther Rantzen that he would give time for the Bill. Many people were alarmed that the ensuing schedule gave too little time for the necessary consultation, reflection and debate on what is, by everyone's reckoning, a complex, morally-serious, and socially-momentous decision.

This essay is our contribution to that condensed debate. It is a (very) heavily revised version of our 2018 report in which the author, Andrew Grey, analysed the meaning of the word 'dignity' with real intelligence, cogency and sensitivity.

However theoretical a discussion of the word 'dignity' may sound, it is not. On the contrary, the concept of 'dignity' stands right at the reactor core of this discussion. Everyone wants people to end their lives in dignity. The problem is we have some – mainly two – radically different ways of understanding what dignity means, and so what the end of life should look like.

The essay explores those meanings and concludes that the meaning which is probably more familiar to most people in this context – i.e. dignity means giving me a choice over how and when I end my life – is inadequate. The alternative view is that dignity means enabling people to live in caring, affirming and loving relationships. This is rooted in Christian thought, in a way that Andrew Grey unpacks albeit in necessarily briefer detail than his 2018 essay, but it is important to stress that the view is not limited to Christians. Indeed, as the essay stresses, many people, religious and not, intuitively *get* what this theological reflection is aiming at.

The essay argues that this conception of dignity-through-relationship is more robust than dignity-through-autonomy but also more demanding. In particular, this view sets before us a tough challenge: if we want truly to honour people's dignity, we must build a society that cares for people as passionately and profoundly as possible, right to the end of the lives. It is to Andrew Grey's great credit that he spells out in considerable detail what this might actually look like, refusing to duck tough questions about what this means in the context of the unmanageable pain, double-incontinence, loneliness, and despair that sometimes scar the end of a life.

This is as important an argument to make now as it was in 2018, but there is a greater urgency, and another dimension, to this debate today which we cannot ignore. It is this: Kim Leadbeater's private members' Bill has some pretty tight restrictions on it, relating to the narrow category of people who should be able to claim assistance in dying (they are discussed by Andrew Grey in the essay). However, these have already come under criticism by campaigners, and indeed other parliamentarians, for being too tight. There is an unavoidable logic to their criticism.

When Esther Rantzen was interviewed about the Bill on the BBC, she said:

> *All I'm asking for is that we be given the dignity of choice.* ***If I decide my own life is not worth living, please may I ask for help to die****. It's a choice. I don't want to pressure anyone either way ... it's the most personal choice, like others, like whether or not to have a baby ... I'm asking for choice.*[1]

If you do understand dignity to mean autonomy, which is exercised as choice, there is no good reason *not* to extend the offer of assisted dying beyond the kind of people envisaged in Kim Leadbeater's Bill. If human dignity = autonomy = choice, society no longer has any cogent reason to deny an individual their choice to die, even if they are not in a terminal condition, not in unbearable pain, or indeed not even in physical ill-health. We may *want* to refuse someone who is, for example, "merely" very depressed but not suffering physically let alone terminally, and who says to you, "I have decided my own life is not worth living, so please may I ask for help to die?" – but we have no cogent reason against this case. If we take this approach, we will inevitably find ourselves on a slope – maybe one with just a very gentle gradient, but a slope nonetheless – without any philosophical brakes to halt our 'progress'.

This is one of the reasons why so many disability campaigners are so alarmed, even at Leadbeater's tightly-construed and seemingly eminently reasonable Bill. Moreover, as Andrew Grey demonstrates in the essay, this is not scaremongering, as the examples of Canada, the Netherlands and Belgium have shown in technicolour over recent years.

We often argue at Theos, that ideas, particularly ideas about who we are as human beings, really matter, and that in the long run it is these deep-sea currents that make the weather. This is one of those instances. Unfortunately, the speed at which this contentious Bill has arrived in parliament, has rather limited the opportunities for that kind of longer-term reflection. It is our hope that this essay will offer some material for debate while it is still open.

Nick Spencer
Senior Fellow, Theos

---

[1] Today - 04/10/2024 - BBC Sounds; at 8:19am (emphases added)

A note on terms

This essay uses the term ‘assisted dying’ to mean a person ending their own life with the assistance of a healthcare professional or any other person. It is often used primarily in the context of a person with terminal illness, who is already perceived as dying – though, as the report will explore, it has since expanded beyond that.

Assisted suicide is sometimes used interchangeably with assisted dying. However, it is often used to mean assisting someone who is not already approaching the end of life, to take their own life. (To avoid this ambiguity, this essay uses the term ‘assisted dying’.)

Physician-assisted suicide refers to doctors providing lethal drugs to patients who have requested them, within the bounds of a law (where this is legal).

The essay is concerned specifically with assisted dying, rather than voluntary euthanasia, which is where someone else (often a healthcare professional) deliberately ends a person’s life to relieve their suffering with their consent.[1]

The forthcoming Bill brought forward by Kim Leadbeater is described as ‘A Bill to allow adults who are terminally ill, subject to safeguards and protections, to request and be provided with assistance to end their own life; and for connected purposes.’[2]

---

1 British Medical Journal, ‘Assisted dying’, https://www.bmj.com/assisted-dying, accessed 13 Oct 2024.

2 UK Parliament, ‘Terminally Ill Adults (End of Life) Bill’, 17 Oct 2024. https://bills.parliament.uk/bills/3774, accessed 24 Oct 2024.

Interviews

Throughout the report, we quote and cite interviews with healthcare professionals with extensive experience in palliative care. In total, we spoke to 12 professionals, for both the first edition of the report (published in 2018) and the second (in 2024), through a combination of face-to-face, telephone and email interviews. The professionals interviewed comprised five doctors, three nurses and four chaplains, who primarily had experience of caring for people with terminal illness in hospitals and hospices. Some of the professionals held religious faith (including Roman Catholic and Protestant), while others did not, and they had a range of views on assisted dying as an issue. In addition, we also spoke to an MP in advance of the publication of Kim Leadbeater's Bill, to get an idea of what the House of Commons (and then Lords) would be likely to debate in late 2024 and to seek their views on this debate.

Introduction

Attempts to legalise assisted dying

In December 2023, Dame Esther Rantzen announced that she was considering assisted dying. She was undergoing treatment for lung cancer, and would consider the option if her condition did not improve. Such a household name declaring this stance, following in the footsteps of people like Sir Terry Pratchett and Sir Patrick Stewart, threw a great deal of weight behind this cause.

Esther Rantzen also called for a parliamentary vote on assisted dying as, in her words, she felt it was "important that the law catches up with what the country wants".[1] Dame Esther's wish was heeded, by none less than Prime Minister Keir Starmer it seems,[2] and in October 2024, Labour MP Kim Leadbeater announced that she was introducing a Private Members' Bill in the House of Commons, following Lord Falconer's introduction of a bill in the House of Lords.

This Bill is the latest of many attempts to legalise assisted dying in England and Wales, an issue which, even when not being actively debated as a Bill, has remained on Parliament's agenda, in one form or another, for 30 years. In 1994, the House of Lords Select Committee on Medical Ethics considered voluntary euthanasia and concluded that there should be no change in the law to permit this practice, as it could be open to abuse.

A decade later, Lord Joffe proposed the Assisted Dying for the Terminally Ill Bill,[3] which was ultimately defeated. In 2014, a further ten years later, Lord Falconer proposed a new 'Assisted Dying' Bill, which passed its initial readings in the House of Lords but ran out of time due to the Parliament ending in March 2015. In June 2015, a Labour MP proposed a very similar Private Members' Bill to the House of Commons, and on 11 September that year, a significant majority of MPs voted against the Bill at its Second Reading.[4]

The issue then returned amidst the Covid pandemic in 2021, when it was introduced into the House of Lords by Baroness Meacher, before running out of time before the end of the parliamentary session. In 2022–23, the Health and Social Care Committee held an inquiry into assisted dying. Its MPs were divided on the issue, and stopped short of recommending legalisation. In other words, this has been a live (and often lively) debate for over a generation.

The current Bill

Kim Leadbeater's Bill, which was introduced into the House of Commons on 16 October but has not, at the times of writing been debated there in detail, is similar to that which Lord Falconer has introduced to the House of Lords. It follows similar themes to previous bills, namely that assistance should be provided for people to end their own life at their request, but only under certain conditions:

- They are terminally ill, with a condition that gets worse and is irreversible;
- They have a prognosis of less than six months to live;
- have written signatures from two doctors, one of whom must be independent.[5]

Leadbeater's motivation is to "give people facing the most unbearable end to their life a choice about what that end is like".[6]

With this Bill proposed, it seems that, as Dame Esther put it, the law may indeed "catch up with what the public wants". A 2023 poll from *The Mirror*[7] commissioned in response to Rantzen’s comments found that 71% were in favour of legalising assisted dying for those with a terminal illness, while just 13% were opposed. A more recent poll by King‘s College London found just under two-thirds (63%) of people supported changing the law. However, it also found that three in five (61%) would be concerned about some people being pressured to have an assisted death if the law were changed, including a majority (53%) of those who want the current Parliament to legalise.[8]

It is also worth noting that the campaigning group Dignity in Dying’s own polling has found support dropped by 6% between 2019 and 2023.[9]

Nonetheless, such strong public support for legalisation may seem decisive. If almost four in five people want a change in the law, surely this ought to happen?

There are several reasons for resisting this simple logic. Firstly, in a representative democracy, the majority does not always support the best or most just policies. For instance, to take a topical issue in the US, a majority of the American public supports mass deportation of undocumented immigrants.[10] For anyone who finds this policy abhorrent, they are unlikely to be persuaded by the simple argument that majority support means the policy must be implemented. One could make similar points about attitiudes to the death penalty for certain heinous crimes, or to the use of torture or ‘enhanced interrogation techniques’ against suspected terrorists by the security services. Public opinion cannot be allowed to shortcut serious ethical and philosophical reflection.

Secondly, it is not simply the job of parliamentarians to determine what is popular and then legislate to achieve it. In the British political system, parliamentarians are trusted to make complex evaluative judgements rather than just reflect public opinion. These decisions require careful consideration of the moral, social and legal implications of policies; responsibilities that individual members of the public may not have the time or resources to make. Whatever one thinks of Brexit itself, the UK's *de facto* experiment with direct, plebiscitary democracy in the 2010s resulted in a period of unparallelled political confusion and acrimony.

Moreover, as John Stuart Mill famously commented, representatives must protect the interests of those in the minority, especially where the majority view is against them. If the people "desire to oppress a part of their number ... precautions are as much needed against this, as against any other abuse of power".[11] The Labour MP we spoke to for this report echoed this sentiment, seeing themselves not as making law for those traditionally with more power – i.e. those who are white, university-educated, professional-class, able-bodied, and wealthy – but for everyone, including – indeed especially – those less able to exercise their rights.

Ultimately, then, it is not so much the sheer weight of public opinion that should decide this complex issue, so much as the reasons for that opinion. And central to those reasons lies the conviction that so many people have, that people should be able to end their lives with dignity, and that this means giving them the choice over when and how to die.

Dignity

The concept of dignity is firmly embedded in the language of the assisted dying debate. The famous (or notorious) Swiss euthanasia clinic is called Dignitas. In Oregon, the state law permitting assisted dying is titled the Death with Dignity Act.

In the UK, the leading campaigning organisation is called Dignity in Dying.

Given how ubiquitous the term is, one might assume its meaning is self-evident. Dignity in dying simply means assisted dying for those suffering. But if such a significant legal change is being proposed on the grounds of dignity, it is essential that we have at least tried to grasp its (various) meaning(s).

This essay will analyse ‘dignity’ as a concept. It will explore the various – essentially two – different conceptualisations of dignity. It will argue that ultimately, human dignity is best honoured by means of our commitment to the objective and inalienable worth of every human being, rather than simply by respecing the choices people have to end their life. This approach is informed by Christian thought but, crucially for a debate of this nature, is relevant to and shared by – many people irrespective of their religious beliefs.[12] It is, in the jargon, accessible to ‘public reasoning’, and not simply a narrow concern for ‘the religious’.

The first chapter explores the meaning of the term ‘dignity’ and its use in assisted dying discussions, particularly its equation with individual choice and control over one’s death. Having argued that this understanding is inadequate, the next chapter presents an alternative understanding of dignity rooted in the inalienable worth of human

> “
>
> **If dignity is understood to be found in personal autonomy and this is expressed through choice, society no longer has any reason to deny an individual their choice to die, even if they are not in a terminal condition, not in unbearable pain, or indeed not even in physical ill-health.**

beings as inherently relational. Following that, the next chapter will explore how the idea of dignity-as-autonomy is inadequate in practice, by looking at what all too often happens in jurisdictions that adopt this logic.

Having explored the meaning of dignity, the following chapters consider its implications for how to give people a dignified death *in practice*, drawing on insights from professionals – doctors, nurses and chaplains – with experience of caring for people at the end of life and those important to them. These interviews offer an essential perspective, grounded in real experience, on the implications of this understanding of dignity for end-of-life care and assisted dying.

The essay will conclude that whilst support for assisted dying very often arises from the desire to treat people with dignity at the end of life, grounding dignity in choice and autonomy means that both philosophically and practically, there is no good reason *not* to extend assisted dying beyond people with terminal illness. If dignity is understood to be found in personal autonomy and this is expressed through choice, society no longer has any reason to deny an individual their choice to die, even if they are not in a terminal condition, not in unbearable pain, or indeed not even in physical ill-health. The examples of Canada, the Netherlands and Belgium have shown how this logic plays out in real life.

In place of dignity-as-autonomy, we favour an understanding of dignity as based on loving relationships, and argue that this leads us to the conclusion that people's needs are best alleviated by greater person-centred care and support, especially palliative care, rather than simply by ending their lives. This means improving access to health and social care, reducing inequalities, and doing everything possible to ensure that people feel valued and loved, rather than perceived as burdens. It is this that will enable people to live and to die with dignity – in the fullest and truest sense of that word.

---

1 https://www.theguardian.com/tv-and-radio/2023/dec/19/esther-rantzen-considering-assisted-dying-if-cancer-treatment-fails

2 BBC Politics on X: "I made a promise to Esther Rantzen before the election that we would provide time for a debate and a vote on assisted dying," Keir Starmer says "I'm very pleased" that I'm able to "make good" on that promise, the prime minister adds https://t.co/Rk9qD1dqS7 https://t.co/0EBERa4tca" / X, accessed 19 Oct 2024.

3 Hansard, House of Commons, *www.publications.parliament.uk/pa/ld200405/ldbills/004/2005004.pdf*, accessed 3 Dec 2015.

4 330 voted against the Bill, compared with 119 in favour, *publications.parliament.uk/pa/cm201516/cmhansrd/cm150911/debtext/150911-0002.htm*, accessed 23rd July 2015.

5 Meaning "a suitably qualified registered medical practitioner from whom the person has requested assistance to end their life ... and another suitably qualified registered medical practitioner who is not a relative, partner or colleague in the same practice or clinical team, of the attending doctor".

6 https://www.theguardian.com/commentisfree/2024/oct/03/assisted-dying-bill-parliament-kim-leadbeater-labour-mp, accessed 3 October 2024.

7 https://www.mirror.co.uk/news/politics/clear-majority-public-support-legalising-31778618

8 King's College London, 'Assisted dying: two-thirds of public back legalisation within this Parliament, study finds', 11 Oct 2024. https://www.kcl.ac.uk/news/assisted-dying-two-thirds-of-public-back-legalisation-within-this-parliament-study-finds', accessed 16 Oct 2024.

9 https://ygo-assets-websites-editorial-emea.yougov.net/documents/DignityinDying_Results_EnglandWales_W.pdf

10 https://www.axios.com/2024/04/25/trump-biden-americans-illegal-immigration-poll, accessed 4 October 2024.

11 J S Mill, On Liberty, https://www.constitution.org/2-Authors/jsm/liberty.htm.

12 This has been attested in numerous studies. See for example, JW Strawbridge et al, 'Religious attendance increases survival by improving and maintaining good health behaviours, mental health, and social relationships', *Ann Behav Med.* 23(1) (2001) pp. 68-74.

1 Dignity through autonomy

In 2015, a husband, father and businessman named Jeffrey Spector took the difficult decision to end his own life at Dignitas. He had inoperable cancer of the spine and was informed that at any moment he could become paralysed from the waist down.

The prospect of this was unbearable for Jeffrey. The *Daily Mirror* quoted his explanation of his rationale for going to Dignitas, citing his "human right to dignity". For Jeffrey, this meant "the ability to have a cup of tea and hold a phone. I want to be able to do those things myself."[1] Dignity was equated with independence. Part of retaining that independence was for him to take control over his death. Jeffrey explained that he "wanted control of the final stages of [his] life".[2] One palliative care doctor we spoke to echoed that many people have this understanding:

> *Dignity in today's parlance means independence – I don't want to be dependent on somebody else, I don't want sickness to show ... When people say, "This is undignified", sometimes they mean, "I'm not independent anymore".* (Interview 3: Doctor)

While Jeffrey's story should evoke compassion from any reader, it should not stop us from looking more carefully at the concept of dignity that underlies his case, and many like it. Like Jeffrey, many of those who advocate assisted dying equate dignity with independence, autonomy and choice. Dignitas asserts that people "are the bearers of human dignity", and that "this is characterised most strongly when a person decides his or her own fate".[3] Parliamentarians who support assisted dying also use the language of dignity. Kim Leadbeater wrote in *The Guardian* in support of her Bill that someone with a terminal condition experiences their illness taking "their life and dignity from them".[4]

> “
>
> **The straightforward equation of dignity with choice is… far from the only way dignity can be understood.**

With such a commonplace association, it is not surprising that many people naturally believe that dignity for those suffering is only made possible through the choice of assisted dying. As one palliative care doctor we spoke to said: “Very sadly, I see people diagnosed with terminal illness who now think the only way to die with dignity is through A[ssisted] D[ying].” (Interview 8: Doctor). The straightforward equation of dignity with choice is, however, questionable, and far from the only way dignity can be understood.

The idea of autonomy

A helpful place to start this discission is the etymology of the word ‘dignity’. Its origins lie in the Latin word *dignitas*, from *dignus*, meaning ‘worthy’.[5] In his book on dignity, Michael Rosen looks at three dimensions of the historical use of this term: high social status (honour), behaviour worthy of respect, and intrinsic value.[6]

In antiquity, the use of dignity seemed to be associated mainly with the first of these – that is, high social status. Cicero equated the term with honour: notably, honour that is only attributable to humans on account of their rational nature. However much this kind of dignity is attributable to humans as opposed to (other) animals, it is also clear that the association of dignity with status is liable to limit the range of people to whom it may be applied. Certain people have dignity; most don’t, or at least they have less than others who are, for example, *more* rational.

The second dimension – dignity through behaviour – can be found in the writings of the Elizabethan philosopher and statesman Francis Bacon. Bacon published a Latin translation of his own book *On the Advancement of Learning*, with the title *De Dignitate et Augmentis Scientiarum*. In doing this, Bacon attributed dignity to a particular pursuit: learning. In this sense, there is a certain worthiness or respect that belongs to particular behaviours. Throughout the text, there are references to dignity, which he clearly associated with worth, such as when he stated "our intent is to balance the dignity of knowledge in the scale with other things, and to estimate their true values according to universal testimony."[7] In this second dimension of the term, there is a respect that is due to persons not by virtue of a particular status, but rather one that is commended by engaging in particular pursuits.

The problem with this understanding, much like the first, is that it implicitly accords dignity to only a limited number of human beings, on this occasion not so much those who occupy high status in society but those who are pursuing some worthy activity or behaving in a suitably worthy way. By this reckoning, by no means *all* humans have dignity.

In a similar vein, people have sometimes tried to ground dignity in certain (uniquely) human capacities, such as our capacity for morality, self-reflection or creativity, but this approach also runs into the problem of excluding those who are unable to fully develop these traits, such as babies and people with severe learning disabilities, or those with advanced degenerative diseases. Such individuals might struggle to make moral choices or be creative, yet we should strongly defend their dignity as human beings irrespective of their moral 'deficiencies'.

The third dimension of the relationship between dignity and worth is the concept of intrinsic worth, the idea that humans do not possess dignity as a consequence of certain capacities they possess or behaviours they exhibit, but rather simply by dint of being humans. This is defined and defended in different ways.

For Immanuel Kant, whose writings have been of seminal importance in this discussion, the dignity (*Würde*) of human beings is intrinsic to them on account of their status as autonomous and rational moral agents. In this regard, although the connection between dignity and choice observed above may seem like it is simply part of a quintessentially modern individualism, in reality, the association of dignity with autonomy is several centuries old.

For Kant, human dignity is based on our status as rational beings capable of moral judgement. In *Groundwork for the Metaphysics of Morals*, he states that "morality, and humanity so far as it is capable of morality, are the only things that have dignity."[8] Dignity here arises from our capacity to act according to moral principles that we autonomously prescribe for ourselves.

In particular, Kant is concerned with two aspects of humanity: our status as ends in themselves, and our ability to be lawgivers.[9] Firstly, human beings – by virtue of their humanity – are never to be treated as means to ends. We cannot simply use humanity as a way of getting what we want – and equally, we should not allow others to use our own humanity as means to getting what they want.[10] For Kant, this means sharing the same ends or aims as others. For example, if I promise to return the book you lend me, I should keep that promise. In doing so, I share your aim for you to get the book back once I have finished with it. If I make a false promise, however, your aim is different to mine – whilst you intend to get the book back, my aim is to keep it for my own benefit. In making that false promise, I fail to show respect to your humanity, because I am treating you as a means to my end (of keeping the book).

Why do we owe this respect to human beings as ends in themselves? For Kant, it is because of their relationship to the moral law. The moral law is something that human beings are, by virtue of pure reason, duty-bound to obey. The moral law is therefore binding: it is not contingent upon additional motives or any desired effects of an action, but is in itself sufficient to obligate any rational person to obey it.[11]

For Kant, an important part of our humanity is that we are both subject to the law, and authors of the law itself. Returning to the earlier point that, for Kant, humanity has dignity insofar as it has the capacity for morality, we can see that a fundamental part of Kant's understanding of human dignity is our autonomy – our ability to be givers of the law to which we are at the same time subject. Absent this, and humans lose their essential dignity and with it a critical part of their humanity. So it is by only respecting the ability of a person to act according to laws they give to themselves through rational deliberation – their autonomy – that we honour their dignity.

The limits of autonomy

If those who advocate assisted dying, following Kant, equate dignity with autonomy and choice, we need to ask whether this is an adequate understanding of dignity. This essay contends that it is not and that respect for autonomy, while important, is ultimately not enough to serve as the basis of human dignity. In essence, it is problematic to equate choice,

> **It is problematic to equate choice, and in particular the choice to die, with dignity. The content of the choice must also affect its relation to human dignity. The fact of choice alone is not sufficient.**

and in particular the choice to die, with dignity. The *content* of the choice must also affect its relation to human dignity. The *fact* of choice alone is not sufficient.

To illustrate this point, ethicists are fond of citing the gruesome case of Armin Meiwes, a German computer engineer, and Bernd-Jürgen Brandes, an engineer.[12] In 2001, Meiwes had posted an advert online asking for a “young, well-built man who wanted to be eaten”. Brandes responded. According to the harrowing evidence subsequently brought to court, Brandes consented to everything that happened to him; the details make for difficult reading. There was no sign that there was any coercion involved in their encounter.

In Kantian terms, Brandes and Meiwes shared the same ends or aims, neither treated the other as means to those ends, and both were acting in accordance with his autonomous wishes. And yet few people would describe the whole affair and the manner of Brandes’ death as ‘dignified’. The law agreed, eventually, and despite Brandes’ informed consent Meiwes was convicted of murder in 2006.

This extreme case highlights the underlying problem with the belief that choice of, and control over, means of death necessarily equates to dignity. There must be something else involved beyond the mere fact of choice that constitutes human dignity.

Beyond this point, there is another problem with the idea of dignity-as-autonomy, which is particularly relevant to the assisted dying debate. Kant's emphasis that dignity is grounded in rational autonomy can seem perilously close to an understanding that humans have dignity on account of their ability to exercise rational autonomy, but that ability is predicated on their *possession of rational and moral faculties in the first place*. Absent these, and humans cannot exercise the rational autonomy that is the basis of their dignity. The relevance of this to the debate, in which the fate of those with advanced dementia or other forms of cognitive impairment is often discussed (and often a source of concern), should be obvious.

> **There must be something else involved beyond the mere fact of choice that constitutes human dignity.**

The problem here is sometimes dealt with by saying that the capacity for rationality and autonomy is inherent within all members of the human species but not dependent on the actual ability of every individual of that species to exercise those capacities. Cognitive impairment, by this reckoning, is not a challenge to the idea of human dignity, because humans *as a species* have rational and moral faculties. Membership of a species that can exercise rational autonomy grants humans dignity, rather than an individual's ability to exercise those characteristics themselves.

Whether this does, in fact, save this particular understanding of human dignity, as being inherent on account of rational autonomy, is highly debatable. What it does do is push the idea of inherent human dignity towards a second approach, which we believe is more credible, and explore in the following chapter.

---

1 Paul Byrne, ‘A final family meal and then 16 hours later tragic dad ends his life at assisted suicide clinic’, *The Mirror www.mirror.co.uk/news/uk-news/final-family-meal-16-hours-5762674#rlabs=8*, accessed 24 July 2016.

2 Ibid.

3 Dignitas, http://www.dignitas.ch/?lang=en, accessed 5 October 2024.

4 Leadbeater, K. ‘Too many people have been condemned to die in misery and pain. My assisted dying bill can change that’, https://www.theguardian.com/commentisfree/2024/oct/03/assisted-dying-bill-parliament-kim-leadbeater-labour-mp, accessed 4 October 2024.

5 The association between dignity and worth is explored further in chapter 2.

6 Michael Rosen, *Dignity: Its History and Meaning* (Cambridge, MA & London, England: Harvard University Press, 2012), pp. 13-31.

7 Sir Francis Bacon, ‘On the Advancement of Learning’, *oll.libertyfund.org/titles/bacon-the-advancement-of-learning,* accessed 21 May 2017.

8 Kant, *Groundwork for the Metaphysic of Morals*, trans. Jonathan Bennett. http://www.earlymoderntexts.com/assets/pdfs/kant1785.pdf, accessed 14 Aug 2016.

9 Those familiar with Kant’s *Groundwork* will also recognise his concern with the principle of universalisability of moral maxims. I have chosen not to focus on this here as it does not seem to be germane to his concept of dignity.

10 JE Hare, *God and Morality: A Philosophical History* (Malden, MA: Blackwell Publishing, 2007), p. 149.

11 Kant, *Groundwork*, pp. 2-10.

12 With thanks to Nigel Biggar who first made me aware of the relevance of this case to the assisted dying debate in seminars at the University of Oxford, 2013.

2 Dignity through relationships

We have seen that proponents of assisted dying often associate dignity with autonomy and therefore with choice, and we have also begun to argue that these cannot in themselves adequately account for what human dignity is. Dignity has, however, been understood in another way.

Dignity in Christian thought

What, then, does Christian thought have to contribute to this debate, and how might that contribution be made accessible and persuasive to those who do not share the beliefs that ground that thought? The answer lies in the idea of "the inviolable dignity of the human person", which is a central concept in Christian thought, as is made admirably explicit in the Catholic Church's *Compendium of Social Doctrine of the Church*: "The whole of the Church's social doctrine ... develops from the principle that affirms the inviolable dignity of the human person."[1]

> “
>
> **The Catholic Church's Compendium of Social Doctrine of the Church says, "The whole of the Church's social doctrine ... develops from the principle that affirms the inviolable dignity of the human person."**

How does Christian thought account for this inviolable dignity? The Catechism of the Catholic Church states that "the dignity of the human person is rooted in his creation in the image and likeness of God".[2] The phrase "the image of God" has been a much – arguably over – interpreted across many centuries, and it was discussed at length in the first edition of this essay, as well as at greater length in the Theos essay *Wholly Living*.[3] Those essays pointed out that the phrase can and has been interpreted in various ways as referring to (a) possessing certain qualities or capacities; (b) being charged with a certain role or duty on earth, or (c) reflecting the deep relational nature of God. Rather than rehearse those arguments in detail here, we want to focus attention the last of these.

According to this approach, being made in the image of God is not a quality or faculty that human beings can either have or not have or possess in varying degrees. It is not predicated on particular capacities or virtues and does not depend on their behaving in a certain way. Individuals may or may not recognise and honour that image to a greater or lesser extent, but ultimately it cannot be lost. Rather, humans are simply made in the image of God as a matter of fact, in the sense that you are the son or daughter of your parents as a matter of fact, irrespective of your inclination or willingness to acknowledge that fact. "Humans are not creatures that are valued by God because they bear the *imago dei*. Humans are creatures that bear the *imago dei* because they are valued by God."[4] Human dignity or 'worth' is inherent and placed in a fundamental relational context: human dignity is based on our being known, addressed, valued, and loved by God.

Such an approach, connecting worth and being cared for, challenges some of the notions of value that are familiar in a capitalist society. Many things, such as an Aston Martin sports car, a Hermès Birkin handbag, or a Patek Philippe watch, are commonly considered to be 'valuable'. They have a clear and huge (monetary) worth. They are what we claim for on insurance if we suffer a theft or a fire. And yet, we instinctively know that it is often less 'valuable' items that are, in fact, much more precious to us. A family heirloom, photograph, or a handwritten letter from a now-deceased friend are the kinds of things that are valuable in the sense we are discussing in this chapter. They have minimal monetary value, but their unique and inherent *relational* value is incalculable.

Take the example of a child's teddy bear. It may be torn, battered, and incapable of performing any useful function. Yet for that child, the teddy bear may be completely irreplaceable.[5] Some families might have pets that are anything but pedigree, which look unappealing and are unable to perform any kind of tricks. By some standards, they seem to be worth very little. Yet their relational value may be immeasurable to their owner. Such analogies steer us towards the idea that dignity resides not in the thing itself but in the fact that *it is loved*. And that is the fundamental claim underlying the Christian conception of dignity: it is based, ultimately, in the love of God, and expressed every day in the way in which human beings love and care for one another.

Dignity, worth and the end of life

We saw in the introduction and the previous chapter that 'dignity' has been taken (or assumed) by many advocates of assisted dying to mean autonomous choice, independence and control, especially at the end of life. However, there is a different and, we would argue, a more powerful understanding of dignity – an inalienable worth attributable to all human beings irrespective of their capacities – that is available to us.

The Christian account argues that this is based on being loved and valued by the God who made us in his image and, in the light of that, it could be argued that this approach is therefore only available to those who hold Christian faith. However, it is also important to recognise that this sense of dignity and worth as rooted in love and relationship resonates powerfully with those who do not hold to the underlying Christian explanation for it. Indeed, there is hardly a single funeral conducted that doesn't, even if unwittingly, underline this resonance. Every time a friend, colleague or relative explains to a mourning congregation that the loved one is missed precisely because they were loved – and usually because they loved others too – they are confirming this understanding of human dignity. Time and again, we reaffirm the notion that our dignity as human beings resides in the networks of love and care into which we are born and live.

> **This sense of dignity and worth as rooted in love and relationship resonates powerfully with those who do not hold to the underlying Christian explanation for it.**

It hardly needs saying that many people do not live in an abundance of loving, supportive relationships. Does that mean they also lack dignity? The answer to that is complex. On the one hand, being lonely, isolated, or rejected can and often does damage people's sense of dignity; that is precisely why we should work to reintegrate such people into networks of love and affirmation. On the other, it is a Christian conviction that even if other human beings give up on you, God does not; that the love of God is constant and unrelenting. Even if you slip out of those relationships that recognise and affirm your dignity, you are still held in a relationship that persists. That dignity is inalienable, and even if one temporarily lacks relationships, they are still worthy of love, and having their value recognised by others.

In the light of this, our task is not to give up on one another, but to meet, help, listen, support and care for those who need it. This applies to those in physical and mental pain every bit as much to those that are well, and to those near the end of life as much as those in the midst of it. Dignity here may involve choice – being in relationship with people entails having agency about that relationship – but it is not exhausted by choice. Ultimately, true human dignity, at the deepest level, consists in this inalienable relational worth, and is demonstrated in being valued by others.

---

1 Compendium of the Social Doctrine of the Church, 107, www.vatican.va/roman_curia/pontifical_councils/justpeace/documents/rc_pc_justpeace_doc_20060526_compendio-dott-soc_en.html, accessed 20 Aug 2016.

2 Catechism of the Catholic Church, Part Three: Life in Christ, Section One: Man's Vocation Life in the Spirit, Chapter One: The Dignity of the Human Person, https://www.vatican.va/content/catechism/en/part_three/section_one/chapter_one.html.

3 Theos, *Wholly Living: A new perspective on international development*, https://www.theosthinktank.co.uk/research/2010/10/10/wholly-living-a-new-perspective-on-international-development

4 A Ritchie and N Spencer, *The Case for Christian Humanism* (London: Theos, 2014), p. 52.

5 A Ritchie and N Spencer, *The Case for Christian Humanism* (London: Theos, 2014), p. 50.

3 Autonomy and the slippery slope

We have presented two contrasting understandings of dignity: one based on autonomy, expressed in free choice, and the other based on relational worth, expressed through love and care. We will now examine the practical implications of the former – grounding dignity in autonomy – for legalising assisted dying.

The association of dignity with autonomy is the assumption of many of those who support the legalisation of assisted dying. In the words of Esther Rantzen, who has been at the forefront of campaigning on this issue and welcomed the Bill:

> *All I'm asking for is that we be given the dignity of choice. If I decide my own life is not worth living, please may I ask for help to die. It's a choice. I don't want to pressure anyone either way ... I'm asking for choice.*[1]

Many who support the Leadbeater Bill would argue that this interpretation of dignity as autonomy applies in the context of terminal illness alone. Indeed the Bill has been criticised by some (including some in parliament) for restricting its focus to the terminally ill and for not going far enough. However, if the Bill is designed to enable people to have the dignity that should be accorded to all humans, and we define dignity in terms of autonomy, it is very hard to see how we can justify limiting the expression of this autonomy to terminally ill people. Would denying someone their considered choice to die even if they were not terminally ill – if, as Rantzen is quoted as saying above, they had decided their own life is not worth living – not be to deny them their dignity? Once autonomy and personal choice are established as the bases for dignity, there is no clear boundary to prevent extending this right to any individual who feels they are experiencing unbearable suffering and therefore requests assisted dying, regardless of their condition. This opens the door to broadening eligibility criteria far beyond terminal illness.

> **Once autonomy and personal choice are established as the bases for dignity, there is no clear boundary to prevent extending this right to any individual who feels they are experiencing unbearable suffering and therefore requests assisted dying, regardless of their condition.**

This is not simply an abstract or hypothetical point – a fallacious 'slippery slope'. In many countries, the legalisation of assisted dying has resulted in exactly this kind of gradual expansion of eligibility criteria. A clear example of this is Canada, where the evolution of laws on assisted dying illustrates exactly how grounding dignity in autonomy can lead to inexorably expanding eligibility.

Medical assistance in dying in Canada

In June 2016, what is termed "medical assistance in dying" (MAiD) became legal in Canada, following a Supreme Court ruling. Much like the proposed law in the UK, it was exclusively available to a specific category of people: those whose death was "reasonably foreseeable" as a result of an incurable condition, causing "intolerable suffering".[2] It was also provided for only under certain conditions, including that people gave informed consent "after having been informed of the means that are available to relieve their suffering, including palliative care". It further deemed three groups ineligible:

- Mature minors;

- Those wishing to access MAiD at the direction of an advance medical directive;
- Those whose only underlying medical condition was a mental illness.[3]

Most of those arguing for the current Bill would also want to exclude those groups. But can it be fair to exclude these groups, beyond the limited category, from their interpretation of dignity? If someone has decreed that they are in too much physical or mental pain to go on living, and it is their considered choice that they want to die, on the assumption that dignity is autonomy it follows that to deny them this right is to deny them their dignity.

Canada illustrates how this happens. Five years after the initial legislation was passed, in 2021, Canada changed its law, following legal challenges to the exclusion of other groups. That law has now been extended, removing the criterion of "reasonable foreseeability of natural death". Now, those with any "grievous and irremediable medical condition" can access assisted dying[4] – "unbearable suffering" applies to many who do not have terminal illnesses. This trajectory demonstrates the philosophical difficulty of maintaining strict limits on assisted dying when autonomy is the foundation for dignity. It results in continual pressure to extend the right to more and more groups, as the exclusion of others based on suffering or disability appears increasingly arbitrary and unjustifiable.

Canada is set to expand the eligibility criteria for MAiD still further, to include people with mental illness – once again a category originally explicitly excluded. This expansion has been postponed multiple times, and is currently not due to come into force until 2027. However, a lawsuit has been filed on the grounds that excluding this group is discriminatory.[5]

> **If someone has decreed that they are in too much pain to go on living and it is their considered choice that they want to die, it follows that to deny them this right is to deny them their dignity.**

This proposed expansion is particularly concerning. Suicide ideation is associated with a number of mental health conditions, as well as medications for those conditions.[6] Even though this expansion has not yet happened, there is already ambiguity in cases that makes it very hard to ensure mental illness is never the reason behind the choice of MAiD. Liz Carr's *Better Off Dead?* documentary, broadcast on BBC in 2024, shares the case of a mother who had what was likely to be a mental illness, but was deemed a physical illness. This enabled her to access medical assistance in dying, against the wishes of both her family and GP, within 48 hours.[7]

This expansion of eligibility raises concerns about how MAiD is applied in non-terminal cases, especially given "unbearable suffering" is loosely interpreted. *Better Off Dead?* also shows the case of a homeless man with back pain after an injury, whose poverty motivated him to seek MAiD. Thankfully he did not proceed – but it is alarming that he was deemed eligible. In a similar vein, the MP we spoke to highlighted that people from poorer backgrounds and marginalised communities are both (a) less likely to have good health (for instance due to less ability to access healthy food or exercise) and (b) less likely to have access to good healthcare (for instance because they live in areas with fewer healthcare services, or they have less access to transport)[8] – and it is feared that this combination would influence them to choose assisted dying if it were to become law in England and Wales.

This is not just scare-mongering. Polling of the Canadian public undertaken by Research Co. in May 2023 found that 43% of respondents were in favour of mental illness being considered as a criterion for MAiD – but more strikingly, half would extend MAiD on the grounds of disability (50%), 28% on the grounds of homelessness, and 27% on the grounds of poverty.[9] Theos's own polling of the UK public in July 2023 found that nearly half of people (49%) supported legalisation for those living with dementia, while 10% supported it for those living in extreme poverty, and 9% for those who are homeless.[10]

Most prominent campaigners on this issue stress that they are only seeking a change in the law for those suffering from a terminal illness – and this is the spirit of the current Bill to be debated in autumn 2024. Yet we should not be surprised that some MPs are already seeking to extend the conditions of the Bill beyond the terminally ill. If dignity is grounded in autonomy, it becomes demonstrably difficult to argue against extending assisted dying to others who experience what they feel is unbearable suffering, such as people with disabilities. As Melanie Reid, a woman who became disabled at the age of 52 after an accident, articulates, "Why do I have to wait until I have something terminal to have that right?"[11]

Indeed, even ahead of Kim Leadbeater's Bill being debated in the UK Parliament, a significant group of MPs have lobbied for the criteria to be extended. As one of them, Lizzi Collinge, had said, "unfortunately suffering is not limited to those who have a terminal illness ... that, I think, needs to be reflected in the law."[12]

So how far should it go? Those with disabilities are especially fearful of the answer to this question. Actor Liz

Carr, who presented the aforementioned documentary *Better Off Dead?* expresses her fears of the implications of an assisted dying law for how society perceives those with disabilities, who may not live as independently as able-bodied people. If, as Jeffrey Spector feared, reaching the point of lacking independence in a terminal illness is equated with lacking dignity, what does that mean for those living with disabilities, for some of whom this is the norm? And if we take this to apply to them too, how can we justify denying them the choice to end their lives? This fear was highlighted in the Health and Social Care Committee's inquiry into assisted dying – namely that "some people who live with disabilities feel as though their lives were not considered equal ... as their specific disability may be included in the criteria that make someone eligible [for assisted dying]."[13]

These fears extend to those with learning disabilities and even neurodivergence, and are not simply hypothetical. In the Netherlands, for instance, both learning disabilities and autism have been given as bases for requesting euthanasia, with once again the motivation for many having been their inability 'to cope with changing circumstances or increasing dependency'.[14] As Frances Ryan writes in the *Guardian*,

> *For anyone who thinks "that could never happen here", consider that it already has in some form. During the height of the Covid pandemic, some people with learning disabilities were given "do not resuscitate" orders without their consent.*[15]

Many of those who advocate for the current assisted dying Bill suggest these countries should be ignored, and that England and Wales would follow the model of Oregon, where since assisted dying was legalised in 1998 it has been limited to those with terminal illness. But even in Oregon there is ambiguity over the involvement of other conditions such as mental health problems – very few people who request assisted dying now have psychiatric assessments to determine whether these are involved. While 28% of people who requested assisted dying had one in the first three years of the legislation, the figure is now just 1%.[16] Multiple suicide experts also cite depression as a reason why many people request assisted dying.[17]

All this shows with sometimes painful clarity that grounding dignity in autonomy makes it increasingly difficult to justify restricting assisted dying to the terminally ill. The fear of many is that this may lead to the normalisation of ending lives due to non-terminal suffering, disability, and even social or economic factors, and the example of countries round the world in which assisted dying has been legalised strongly suggests that these fears are wholly justified. Such concerns emphasise the importance of our alternative view of dignity – rooted in relational worth, where the value of human life is recognised beyond autonomy and choice.

---

1 Today - 04/10/2024 - BBC Sounds, at 08:19

2 'End-of-Life Law & Policy in Canada', Health Law Institute, Dalhousie University, http://eol.law.dal.ca/?page_id=238, accessed 5 Oct 2024.

3 'Bill C-14. 2016. An Act to Amend the Criminal Code and to Make Related Amendments to Other Acts (Medical Assistance in Dying). 1st Session, 42nd Parliament' cited in Konder, R.M. and Christie, T., 'Medical Assistance in Dying (MAiD) in Canada: A Critical Analysis of the Exclusion of Vulnerable Populations', Healthc Policy. 2019 Nov; 15(2): 28–38.

4 'Infographic: Canada's new medical assistance in dying (MAID) law', Government of Canada, https://www.justice.gc.ca/eng/cj-jp/ad-am/infograph.html, accessed 5 Oct 2024.

5 'Canada's assisted-dying law faces constitutional fight for excluding mental disorder'. *CTV News*, https://www.ctvnews.ca/canada/canada-s-assisted-dying-law-faces-constitutional-fight-for-excluding-mental-disorder-1.7006167, accessed 5 October 2024.

6 'Suicidal feelings', Mind, https://www.mind.org.uk/information-support/types-of-mental-health-problems/suicidal-feelings/causes-of-suicidal-feelings/#CommonCausesOfSuicidalFeelings, accessed 5 Oct 2024.

7 *Better Off Dead?*, op. cit.

8 NHS England, 'Deprivation', https://www.england.nhs.uk/about/equality/equality-hub/national-healthcare-inequalities-improvement-programme/what-are-healthcare-inequalities/deprivation/, accessed 13 Oct 2024.

9 Most Canadians Back Status Quo on Medical Assistance in Dying – Research Co.

10 *A matter of life and death*: Theos polling on assisted dying - Theos Think Tank - Understanding faith. Enriching society.

11 *Better Off Dead?*, op. cit.

12 Turner, C. 'Extend assisted dying to those without terminal illness, say Labour MPs', *The Telegraph,* 5 Oct 2024. https://www.telegraph.co.uk/politics/2024/10/05/widen-access-to-assisted-dying-say-labour-mps/?ICID=continue_without_subscribing_reg_first, accessed 6 Oct 2024.

13 Health and Social Care Committee, Assisted Dying/Assisted Suicide: Second Report of Session 2023–24, 29 February 2024. https://publications.parliament.uk/pa/cm5804/cmselect/cmhealth/321/report.html#heading-2, accessed 6 Oct 2024.

14 Tuffrey-Wijne, I. et al, 'Euthanasia and assisted suicide for people with an intellectual disability and/or autism spectrum disorder: an examination of nine relevant euthanasia cases in the Netherlands (2012–2016)', BMC Med Ethics. 2018; 19: 17, https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5838868/.

15 Ryan, F., 'I'm glad the debate on assisted dying is forging ahead. But few understand why it frightens so many', *The Guardian*, 29 Feb 2024, https://www.theguardian.com/commentisfree/2024/feb/29/ministers-assisted-dying-disabled-people-euthanasia, accessed 5 Oct 2024.

16 BMJ Group, ‘Critical data gaps on doctor assisted deaths in Oregon amid rise in participants’, 4 Oct 2023. https://bmjgroup.com/critical-data-gaps-on-doctor-assisted-deaths-in-oregon-amid-rise-in-participants/, accessed 13 Oct 2024.

17 Muskin PR. ‘The request to die: role for a psychodynamic perspective on physician-assisted suicide.’ JAMA. 1998 Jan 28;279(4):323-8; Vachon ML. ‘In the terminally ill, a wish to die is a manifestation of depression and should be treated accordingly.’ Clin Oncol (R Coll Radiol). 2004 Aug; 16(5): 319-20.

4 End of life concerns

If dignity is re-conceived in relational terms, where it is honoured by demonstrating people’s worth through love and care, we need to ask the difficult question, can this be sufficient for those who want assisted dying? It is all well and good to talk about love, care and dignity, but there is a hard reality here – namely people feeling such pain or despair that they request assistance to die. Can ‘dignity-as-love’ really respond to that?

To answer this, we need to examine carefully why exactly it is that people do request assistance in dying, rather than simply relying on assumptions and hearsay. To do this we can draw on the evidence from the interviews we conducted, as well as wider empirical data from various studies. These suggest four common reasons why people request assisted dying:

- Feeling their suffering is unbearable;
- Fearing humiliation from progressive illness and the dying process;
- Fearing a loss of control;
- Not wanting to be a burden on services or people close to them.

For each of these, professionals not only articulated the reasons people asked for assistance in dying but also described the ways they could respond to these fears and concerns in such a way as refused their stated desire (because it was illegal) but instead treated them with love, care and – therefore – *dignity*. In all their responses, it was clear that their relationship with the person was essential to alleviating the concerns.

Suffering

Theos polling for the research project *Love, Grief and Hope* reported how fear of "suffering" or "being in pain" was people's top fear concerning their own deaths.[1] It was not a surprise then to hear this confirmed by those people we spoke to. Some professionals spoke about people who responded to their own suffering – especially pain – by requesting assisted dying:

> *The occasional person does [mention assisted dying] – if they're in intractable pain, that, "Oh I wish you could give me something, but I know you can't."* (Interview 6: Chaplain)

However, in many cases, it was those close to the person, witnessing their suffering, who expressed their concerns. Analogies with suffering animals being put down were common – but professionals did not regard these comparisons as fair or accurate.

> *The phrase that they all say is, "You wouldn't treat an animal like this, you would put it down". But actually, it doesn't quite follow because we don't offer animals very good palliative care, do we?* (Interview 1: Doctor)

Can palliative care address these concerns? For many people, their suffering was relieved and symptoms managed by care professionals, which meant they no longer wanted assisted dying. What they had really wanted was not assisted dying, but relief from suffering.

> *I have certainly known people who have actually, their views have shifted. Sometimes people have this view because maybe they are in a lot of pain, or their symptoms are just so bad, they can't imagine them being improved. And sometimes with the right medication, with the right level of support, people can come*

> *to feel differently, and say, "I never imagined that my life could feel worth living again, but in fact now it does".* (Interview 7: Chaplain)

These views were sometimes shaped by people perceiving their relative suffering terribly, when this was not a reflection of reality.

> *Often [the request for assisted dying] comes from relatives, and I think that is often an expression of their distress, because they'll say, "Well you wouldn't treat an animal like this", but then you look at the patient and actually, they're in bed, they're completely comfortable, look really peaceful, asleep. And you think, well, the patient doesn't look like he or she is suffering – actually, they look very peaceful. But it's the distress of the relative ... that is unbearable to them, so they just want that situation to go away.* (Interview 1: Doctor)

In most cases where people want their suffering to end, therefore, it is possible for care professionals to relieve their suffering through the right medication. What, however, happens in those few instances where this medication isn't enough, and people continue to be in unbearable pain? Professionals mentioned that in these rare instances, it was legally and medically possible to increase their sedation. However, they also mentioned that once they had made clear that this option was possible, very few people actually asked for it.

> *I do sometimes ... say, "I won't ever do anything that will kill you, but if you tell me this is intolerable, I'll ensure that you sleep." And if you give them that option, I very rarely have to actually increase someone's sedation. Sometimes they just want to feel calmer.* (Interview 3: Doctor)

Some of the drugs that can make the person more comfortable may also have the side-effect of shortening a person's life.

> *If somebody is coming to the end of their lives, and they want to be less aware ... a doctor will try to honour that – not in the sense of ... giving them a drug which will kill them, but in terms of giving them a drug which will make them more comfortable, and may have the side-effect of actually meaning maybe that they don't live quite so long.* (Interview 7: Chaplain)

It is important to note that this option is both legally and morally distinct from actively intervening with the intention of ending someone's life, based on the long-standing philosophical and theological concept of double effect.[2] According to the doctrine of double effect, it is morally permissible to commit an act that causes harm as long as this is an unintended effect of the act, rather than the intention of it. Aquinas' example is killing an aggressor in self-defence – if the person defending themselves commits an act which causes the death of the aggressor, it is morally permissible as long as their intention was to save their own life.

Some may find this distinction between an act with intended effects and one with unintended (but foreseen) side-effects unconvincing. However, as theologian and ethicist Nigel Biggar observes, if there were no distinction between these two, there would be no distinction between involuntary homicide and murder.[3] There is, therefore, a morally significant distinction between administering symptom-relieving drugs to a person that may have the effect of shortening their life, and giving or assisting a person to take drugs that have the explicit purpose of ending their life.

In response to those who advocate assisted dying as a means to end a person's suffering, we would argue that it is possible in most cases for medication to alleviate a person's suffering without any additional effects, and in those rare instances where this medication is insufficient, there is a morally and legally permissible option of administering drugs to make them more comfortable even if these drugs may shorten their lives.

Fear of humiliation

> *As noted above, in some cases people mention assisted dying not so much because they fear the suffering they will encounter, but the humiliation they may face as their body deteriorates and they approach the end of life. For some people, this is an explicit fear of losing their dignity. "I think I hear the term [dignity] used most around physical care... like, 'I need to have a nurse to wash my bum now ... I've lost my dignity.'"* (Interview 1: Doctor)

Just as it is obvious why people fear unbearable suffering, it is easy to see why people would fear humiliation from nakedness or incontinence. However, there are problems with the assertion that dignity is incompatible with this kind of dependence on others. What does this mean for people with disabilities who often have social care needs like this? One interviewee we spoke to was horrified at how some people, who otherwise advocate for those with disabilities, have suggested their motivation for wanting an assisted dying law is that they themselves would rather die than need someone to wipe their bottom: "It's revolting to suggest being in need of personal care means one's life is less worth living."

In such cases, it becomes imperative that professionals caring for the person attempt to do what is necessary to alleviate any humiliation. With fears of nakedness and other aspects of care, it is essential that professionals treat the person with dignity. Canadian doctor Harvey Max Chochinov developed a ‘Dignity in Care’ framework for healthcare professionals, one aspect of which deals with privacy. One of its key “principles for care that enhances dignity” advises the professional to “safeguard the person’s privacy: remember that procedures that may be routine for those who work in health care are not routine for most patients.”[4] Chochinov also explains that there are other key ways to honour this dignity and enhance trust and connection between the professional and the person they are caring for. “Taking the time to ask patients their permission to perform an examination will make them feel less like a specimen to be poked and prodded and more like a person whose privacy is theirs to relinquish under mutually agreed conditions.”[5]

The professionals we spoke to told us that there are various options for dealing with symptoms such as incontinence. They made clear that communicating with the person was essential, to understand what they most feared and what their priorities should be for addressing these fears.

> *I think the starting point ... is communication, and getting the people to describe or communicate with you what it is that they need, and then, where possible you deliver that. So if someone says, “The last thing in the world I want is to be incontinent of faeces” ... we can instigate regimes where we can use things like bowel irrigation ... a medication regime, so that we can almost control when the bowel motions are likely to happen, and then manage the visitors ... on the days where they’re likely to happen.* (Interview 11: Nurse)

In many cases, then, the humiliation that people fear can be mitigated by preventing the symptoms they fear will humiliate them. But, again, we must ask, what happens for those whose symptoms can't be prevented? Palliative care professionals are often experienced in caring for people under such circumstances.

> *[It's important that] when it's dealt with, it's done without any embarrassment to the individual, and it doesn't become a big issue for them or for anyone else. And all the care staff ... devise strategies and their communication skills are such that people shouldn't feel degraded at all – they should just feel that it's part of their illness, and that it's managed as best as possible.* (Interview 11: Nurse)

Sometimes other unavoidable symptoms can cause an unpleasant appearance or smell, which people may experience as humiliating. In such situations, how those around them respond to these symptoms is key, remembering and reflecting their inalienable relational worth as a human being.

> *This particular gentleman that I've been seeing recently, who's got [a] ... facial tumour ... all the way through that conversation, I'm looking at his good side ... trying to show by my whole body language, by how I'm focused on him ... that actually that's just a periphery ... he's a valued human being.* (Interview 4: Chaplain)

Once again, then, a major reason why people consider assisted dying can be addressed in the way in which people relate to them: by doing whatever they can to prevent symptoms which they find humiliating, and, where these are unavoidable, to respond in a way which shows the person that they are valued irrespective of their condition, thereby honouring their dignity.

Fear of losing control

In some instances, what people fear is not really the humiliation from symptoms themselves, but from their lack of control.

In *Better Off Dead?* Carr interviews a Canadian doctor who administers MAiD, who cites the number one reason people request it as "desperately wanting control". The doctor even states that she is of the view that for some who request MAiD, "what [they] really needed was more drugs" (to manage their symptoms), but that ultimately she must accede to their request.

This is something that people may be especially likely to fear with debilitating illnesses such as motor neurone disease (MND), which gradually cause the person to lose their communication and motor skills:

> *I think sometimes [asking for assisted dying] is to do with that sense of lack of control – maybe somebody has always been very active and in charge of their lives, and the prospect of increasing weakness and debility is really, really hard.* (Interview 7: Chaplain)

Professionals made clear that how the person is communicated with is fundamental in these situations. Building a relationship of trust with the person is crucial to helping alleviate their fears of losing control.

> *They do sometimes plead for euthanasia because they're afraid of what's coming. There's something about relating to them in a way that, if you can get their trust, you can make the whole thing much better.* (Interview 3: Doctor)

It was also important in such circumstances to recognise what the person could control, however limited, and ensure that they were given this opportunity. In some cases, this can be around what seems like even trivial matters.

> *I think it's important for people, especially when ... it feels that they've lost everything ... to be able to have some control over whether they see you or not. So I think ... it's really important for me to say, "Is it a good time or not? Do you want me to come?" or, "if you want me to go away, that's fine." They have control over very little else.* (Interview 4: Chaplain)

In addressing this fear, it is once again important for professionals to consider the person's wishes and needs, and to meet these as far as possible.

> *We would always try to listen to what [the person's] priorities were and wishes were, and let them have choice as much as it's possible in what they want for the end of their life.* (Interview 1: Doctor)

This is especially important where a person fears loss of control. Respecting their wishes can help restore a feeling of some control, as well as enabling them to feel that they are valued – the source of their true dignity.

Fear of being a burden

For some of those who consider assisted dying, their fear is not around their own suffering, humiliation, or loss of control, but of the impact of their illness on others. They may fear being a burden on people who are important to them.

> *Some of the urge for assisted dying comes from compassion for family ... 'I don't want to be a burden.'* (Interview 3: Doctor).

Another nurse had fears

> *About vulnerable people feeling pressured, and opting for it to not be a burden to their families.* (Interview 12: Nurse)

This is, of course, a major concern among those against assisted dying and has been shown to be a legitimate fear in several countries where assisted dying is legal. In 35.3% of cases of MAiD in Canada in 2021, "perceived burden on family, friends and caregivers" was cited as a reason for suffering, while since it was legalised in 1998 in Oregon – a law, as we have noted, often cited by assisted dying campaigners as a model to follow – almost half of people who have pursued it have cited the same concern of being a burden.[6]

Since it was legalised in 1998 in Oregon – a law, as we have noted, often cited by assisted dying campaigners as a model to follow – almost half of people who have pursued it have cited the same concern of being a burden.

Other people fear being a burden on a broader system, such as the NHS or the social care system.

> *You know, sometimes, you get people that won't even press the button [to call for help], because they feel they're just putting the nurses out or something.* (Interview 9: Chaplain)

This is surely the most tragic reason why people request assisted dying, and goes against all we have said about people's dignity – their intrinsic worth because they are valued and loved, which demands that they are cared for in supportive relationships to the very end of their lives.

Many worry that if assisted dying were legalised, this fear of being a burden would influence people's decision to end their own lives. It is not hard to imagine this being the case. The MP we spoke to was deeply concerned that people would be motivated to make the choice if assisted dying were to become legal, as "we do not have a perfect health and social care system ... the NHS is on its knees ... social care is non-existent for many people ... hospices are struggling to meet demand." Already older people and those with health conditions are likely to feel perceived as a burden. One report published in 2013 found that 61% of people over 65 felt that society saw them as a burden and 57% thought that the media encouraged the idea that older people are a problem for society. The recent Covid pandemic exacerbated these concerns, with the view often espoused that older people and those with underlying health conditions were placing a huge burden on younger, healthier people who had huge restrictions imposed on their lives.

These attitudes inevitably lead to fears of pressure to opt for assisted dying, so as to relieve communities and society of their perceived burden. One doctor said:

> *Assisted dying ... has a financial benefit, not only to families but to government as well. You know ... the pension crisis, the cost of healthcare, the challenges on the NHS ... all the negative language around ageing. If we started to put assisted dying on the agenda, you can probably expect some smart civil servant somewhere to say, you know, "We've got the solution".* (Interview 5: Doctor)

Other studies report people who fear "the idea of a society not being able to afford all the people living as long as they are. And some other country ... saying, 'Look when you reach 80, you have to have euthanasia'."[7]

This may seem like an extreme product of the imagination to some. But worrying evidence from Canada suggests this trajectory is not implausible. For instance, veteran and retired Paralympian Christine Gauthier, who had spent five years attempting to get a ramp installed in her home, reported she was "shocked and in despair" when a caseworker suggested that they could give her MAiD – and even offered to supply the equipment for it.[8] In a similarly sinister case, Roger Foley, a 45-year-old man with a severe disability, testified before a Parliamentary committee that when he was advocating for assistance to live at home, he was threatened with having the vital care he needed withdrawn. He said: "I felt pressured by these staff raising assisted dying rather than relieving my suffering with dignified and compassionate care."[9] If assisted dying is legalised to provide what is seen as the dignity of autonomy, this is undermined by the serious risk of coercion and pressure evident here.

In the UK, some commentators have publicly argued along these lines. Journalist and former MP Matthew Parris has argued that legalisation of assisted dying is inevitable for "Darwinian" reasons, as "the cost of prolonging human life way past human usefulness will impose an ever-heavier burden on the community", given that "the cost of medical provision in Britain eats into our economic competitiveness."[10] Baroness Mary Warnock, one of Britain's leading moral philosophers, argued that older people with dementia should consider ending their own lives because they are a burden on their families and the NHS – indeed, they may have a "duty to die".[11] As dementia expert June Andrews says in response to this, "I can think of nothing more tragic than where the person wishes to kill himself or herself because of the burden they are to other people. Other people have given them the view that they are a burden."[12]

In particular, Andrews' last sentence on this is pertinent: if a person feels that they are a burden, this is a view that is influenced by others, as it is intrinsically related to their connection with others. A person cannot consider himself or herself a burden if there is no one to whom they are a burden. With the ability to influence a person's perception of themselves in this way, it is incumbent on those around them to convey that, far from being a burden, they are valued. This can be conveyed by the people who are important to them, and must also be conveyed by professionals. The person should be left in no doubt that they are worth spending time and resources on to ensure that their needs and wishes are met as far as possible. In the words of the vicar and commentator Giles Fraser, "I do want to be a burden on my loved ones just as I want them to be a burden on me – it's called looking after each other."[13]

Of course, there will be times when those they fear burdening, if they are a partner or family member for example, may legitimately feel that they are not able to care for the person. In such circumstances, it is important to find solutions such as home care, or moving into a care home or hospice. However, the message they communicate to the person at this time is of critical importance: moving into a new care setting is to enable them to receive the high-quality care they need and deserve, and to enable the person who had been their informal carer to continue their relationship with them. This is a very different

> **In a study by the Dutch National Institute for Health, it was found that loneliness or social isolation was a key factor in over half of the euthanasia requests reviewed.**

message from the suggestion that the person is a burden from which their carer wishes to be relieved.

Evidence from the Netherlands, where euthanasia and assisted dying have been legal since 2001, also suggests that relationships can influence whether people consider this option. In a study by the Dutch National Institute for Health, it was found that loneliness or social isolation was a key factor in over half of the euthanasia requests reviewed.[14] Once again we see the fundamental importance of relationships for ensuring a person feels valued, and does not therefore consider the termination of their own life as preferable to living. Whether by alleviating the person's suffering, helping them to avoid humiliation or to deal with the loss of control that comes with progressive illness, or by enabling them to feel valued and worth investing in, professionals and those close to a person approaching the end of life can play a significant role in addressing their concerns and helping them to feel that assisted dying is not a preferable option over living and being cared for by people who value them.

To enable this, a well-funded and resourced palliative care system is of course essential. Palliative care has not been intentionally under-resourced in countries where assisted dying has been legalised. However, there are areas where it is lacking. For instance, in Canada, some people are not receiving palliative care until just before they die. Age, location and diagnosis are also barriers to some people receiving palliative care.[15] In the Netherlands, it has been observed that palliative sedation is becoming widespread – as opposed to England where it is only used specifically to decrease symptoms.[16] We cannot prove that assisted dying has been a contributing factor to these trends, but we would suggest that investing to avoid any such gaps in palliative care should be the priority in

England and Wales, instead of intervening to end people's lives. This would be a more effective way of honouring the dignity that should be accorded to them.

This chapter has looked at the various reasons why people tend to request assisted dying. Very few people welcome suffering (let alone unbearable suffering), or the humiliation or loss of control that can come with a degenerative illness, and many people do fear being a burden on their loved ones or even public services. If one is insistent that human dignity resides in our autonomy, it is easy to see why assisted dying is the obvious option here.

But not only is this approach risky; the assisted dying made available to a terminally ill patient in unbearable suffering should also, by this logic, be made available to the mentally ill patient who is utterly convinced their life is not worth living. It is also not necessary because, as our interviewees repeatedly pointed out, the right approach to caring for the ill, based on an understanding of their dignity that is grounded in right relationships, can make a significant and positive difference to their lives, even at the end. In our final chapter, we turn towards a fuller picture of what that might entail. What does palliative care which truly honours this dignity look like?

---

1 Love-Grief-and-Hope.-Emotional-responses-to-death-and-dying-in-the-UK.pdf

2 Aquinas, *Summa Theologica IIaIIae*, q. 64, a. 7, *newadvent.org/summa/3064.htm#article7,* accessed 21 May 2017.

3 Nigel Biggar, *Aiming to Kill: The Ethics of Suicide and Euthanasia* (London: Darton, Longman and Todd, 2004), p. 67. Involuntary homicide does not, as Biggar later points out, absolve the person of ultimate responsibility for the person's death, but rather, is morally distinct from killing someone with the explicit intention of ending their life.

4 HM Chochinov, 'Dignity in Care: Approach', *www.dignityincare.ca/en/approach.html*, accessed 21 May 2017.

5 HM Chochinov, 'Dignity and the essence of medicine: the A, B, C, and D of dignity conserving care', *BMJ* 334 (2007), p. 186.

6 Health Canada, Fourth annual report on Medical Assistance in Dying in Canada 2022 (October 2023), cited in Health and Social Care Committee, op. cit.

7 Tomlinson et al, Euthanasia, p. 724.

8 CTV News, 'Paralympian trying to get wheelchair ramp says Veterans Affairs employee offered her assisted dying', 3 Dec 2022. https://www.ctvnews.ca/politics/paralympian-trying-to-get-wheelchair-ramp-says-veterans-affairs-employee-offered-her-assisted-dying-1.6179325, accessed 17 Oct 2024.

9 House of Commons Canada, JUST Committee Meeting, 10 Nov 2020. https://www.ourcommons.ca/DocumentViewer/en/43-2/JUST/meeting-6/evidence, accessed 17 Oct 2024.

10 Parris, M. 'Euthanasia is coming – like it or not', *The Spectator*, 31 March 2024. https://www.spectator.co.uk/article/matthew-parris-assisted-dying-lives/, accessed 6 Oct 2024.

11 Martin Beckford, 'Baroness Warnock: Dementia sufferers may have a "duty to die"', *The Telegraph*, 18 September 2008, *www.telegraph.co.uk/news/uknews/2983652/Baroness-Warnock-Dementia-sufferers-may-have-a-duty-to-die.html,* accessed 21 May 2017.

12 June Andrews, *Dementia: The One-Stop Guide: Practical advice for families, professionals, and people living with dementia and Alzheimer's Disease* (London: Profile Books, 2015), p. 97.

13 I want to be a burden on my family as I die, and for them to be a burden on me | Giles Fraser | The Guardian

14 Simon Caldwell, 'Most euthanasia deaths linked to loneliness, says Dutch study', *Catholic Herald* 18 February 2016, www.catholicherald.co.uk/news/2016/02/18/most-euthanasia-deaths-linked-to-loneliness-says-dutch-study, accessed 21 May 2017.

15 Government of Canada, 'The Framework on Palliative Care in Canada—Five Years Later: A Report on the State of Palliative Care in Canada', 15 Dec 2023. https://www.canada.ca/en/health-canada/services/publications/health-system-services/framework-palliative-care-five-years-later.html#a2.2, accessed 13 Oct 2024.

16 Christian Network Europe, ‘Dutch doctors worry palliative sedation becomes the norm at the end of life’, 22 Feb 2023. https://cne.news/article/2609-dutch-doctors-worry-palliative-sedation-becomes-the-norm-at-the-end-of-life, accessed 13 Oct 2024.

5 Dignity at the end of life

If the concerns of those who choose assisted dying could be alleviated by reconceiving dignity in relational terms, rather than autonomy, what does dignified death mean, and how can we achieve this?

In this chapter, we will explore the insights gained from our interviews with professionals regarding the key elements of what it means for a person to die with dignity. We conclude that truly dignified dying demands relationships in which the dying person and those things important to him or her are truly and deeply valued, and that we must therefore invest in health and social care, vastly improving access to high quality palliative care and reducing health inequalities

Dignity in dying

Despite the way in which dignity has routinely been associated with autonomy, choice and assisted dying in the popular imagination, all of the professionals interviewed, whatever their views on assisted dying, testified that most of the people they had cared for had had dignified deaths without this kind of choice being available to them.

So what *is* necessary for a dignified death? As we have argued, relationships are essential for honouring people's dignity, and when caring for people at the end of life, the existence of such relationships *that value the person for everything they are and have been* is essential. The professionals we interviewed emphasised this point throughout our conversations.

> *A lot of what I'm doing [is showing], "You are important. What you say is really important. Your life has been of value."* (Interview 4: Chaplain)

Professionals communicated people's value in several ways. Key among these was listening to and understanding the person as a person, not simply as a patient. This is central to the phenomenon of person-centred care, where professionals recognise the need to understand the patient as a person with their own background, history, needs, and wishes.

> *I think part of the dignity, for me, is ... not treating them just as a patient; treating them as an individual, getting to know them as an individual, understanding who they are and where they come from, and knowing a bit more about them.* (Interview 11: Nurse)

Listening to people approaching the end of life had practical benefits. By understanding them better, professionals could understand the kinds of things they needed and asked for, and relate them to what they knew about the person. For instance, one nurse mentioned caring for ex-military men, many of whom fought in World War II, who wanted to be smart, shave every day, and keep up the kind of presentation that had been their habit.

Human nature is inherently relational, and this is no less true when a person is at the end of their life. These relationships may come in different forms including a person's family, partner, friends, neighbours, religious communities, work colleagues, fellow members of special interest or peer support groups, and even (sometimes especially!) pets. It is important that care professionals honour these relationships, again by listening to and valuing those who matter to the person and make up their network of relationships.

The professionals we spoke to testified to the difference this could make to the person having a good death. One doctor emphasised that the people who matter to the dying person should be included as part of the process, not simply as an afterthought.

> *Families are an important part of the process ... to make sure that they are on board with the patient's wishes, ideally as part of a unified group of people who are talking about all the same things at the same time.* (Interview 2: Doctor)

People are more likely to have a better experience at the end of life if those who matter to them are also involved in the process. This is because in many cases, the happiness of those people is also important to the dying person.

Some of the professionals interviewed also pointed out that at times there may be conflict between the expressed wishes of the dying person and those around them. Such cases raise difficult questions. One chaplain told us about a dying person who made arrangements for her funeral with him, which would involve him conducting the service. The person died soon after this and the chaplain only then discovered, after speaking to the person's family, that they did not want the chaplain to be involved in the funeral. In that situation, the chaplain felt it was important to recognise the family's needs in their grief.

> *We ended up saying, "As her husband, her family, your needs are important too, so we're able to let go of those previous arrangements." And it was the dignity of how the family were dealing with that that mattered ... you have to ... respect that dignity goes beyond the wishes of the person sometimes.* (Interview 9: Chaplain)

The chaplain said some prayers with the family which helped partly to meet the wishes that the dying person had expressed. But in the situation of the family's bereavement, he was able to recognise the importance of the family's dignity. Whilst the wishes of the person at the end of life should be considered first, the wishes and needs of those important to them must also be regarded as important, and taken into consideration.

What does a dignified death look like?

Having recognised this, we must now consider in more detail what matters to people at the end of life. Although each person's wishes and needs are, of course, individual, there are certain common themes that emerged from our interviews with professionals. Many of these are also reported in *What's important to me,* a national review of the choices that people want at the end of life.[1] The findings considered here relate to key aspects of people's needs at the end of life: physical, social, psychological, and spiritual. These are the four elements of 'total pain' at the end of life identified by Dame Cicely Saunders, founder of the modern hospice movement, which shaped the modern understanding of palliative care.[2]

Meeting all of these needs depends on professionals valuing the person at the end of life and those important to them, to ensure these wishes are met. It will be evident that relationships with professionals and others are central to enabling a person to have a dignified death.

Acceptance

The most frequently recurring theme in our interviews was that acceptance was important for a person to have a good and dignified death. This acceptance not only influenced the person's psychological state, but also their physical symptoms at the end of life.

> *The patients that don't kind of get their heads around where they are in their disease process and that can't really accept that they're dying, often suffer a lot more agitation and can be more difficult to manage symptomatically... but the people who are able to ... talk about what's going on, and be in some way ... at peace with what's going on, tend to have less in the way of agitation and symptoms.* (Interview 1: Doctor)

For people to accept their own death, they depend in part on professionals to communicate to them that they are approaching the end of life (insofar as this is consistent with their wishes). Several of the professionals nonetheless mentioned the need for more honest and open communication about dying. It is essential that those who wish to know when they are approaching the end of life are communicated with openly to ensure they can come to a place of acceptance about their dying.

Acceptance of death also has practical implications for treatment. One doctor observed that some healthcare professionals continue to pursue treatments when the person is clearly dying, and the patient could have a better, more peaceful death, if their care focussed on comfort. This risks the person dying in the anonymity of hospital instead of in more comfortable and more personal surroundings.

However, even when professionals have accepted and communicated that a person is dying, it can be very difficult for some people to accept their situation. The professionals we spoke to mentioned tragic instances where people had not accepted what was happening to them. In contrast, when people were able to accept that they were dying, this made a huge difference to their death:

> *I'm reminded of a patient who was a young-ish man (I think he was late fifties) – and I told him he had ... not long to live, and he said, "Well, doc, you know, I've had a good life – I've seen my children grow up". And I was really struck by his peace.* (Interview 3: Doctor)

As we have observed, the dying process also includes the people who are important to the person. In some cases, the person themselves could accept their impending death, but those around them were unable to. Some professionals mentioned that this even happened in some cases where a person was dying in their eighties or nineties.

Through a combination of clear, compassionate communication and supportive attitudes, professionals caring for a person at the end of life can help them to accept their own death, enabling them to develop peace of mind as a first step towards dying with dignity.

Dying in peace

Sometimes, people who have accepted their impending deaths still do not experience peace of mind in their final days and weeks. Professionals spoke of people who had received all of the medical care they required but were still agitated as they approached death. They reported a number of reasons for this. In some cases, the issue was simply missing what was comfortable and familiar to them. However, for some people, there are deeper problems, such as unresolved issues with people who are important to them:

> *[I see] families who've been estranged for a few years. If you actually get these people to a point where they'll have the conversation with you, you'll be surprised how many will say to you, "You know what, I haven't spoken to my son or my daughter*

> *or whatever for [ten years], and it would just be nice to have one more conversation with them, so I could say this or this." And things like that are easy to do ... if you get the consent and you get the people ... a phone call ... it can make such a difference.* (Interview 11: Nurse)

In some cases, the issues on people's minds as they approached the end of life were not so much about unresolved tension or estrangement, but more practical. One example of this illustrates, as observed earlier, that the people who are important to someone are often not just relatives.

> *I can remember one chap who, the one thing that was stressing him more than anything else, he was the treasurer for his bowls club, and he just needed to get some money paid into the ... club's account. And once that was done, he was a different fellow, he was like, "Thank goodness for that, I can relax now."* (Interview 11: Nurse)

Once again, we can see clearly the profound impact that a person's relationships can have on their experience of dying. In some cases, people may not be estranged, or have unresolved personal or practical issues, but simply want to see a person they love again. Clearly the people who are important to someone can be essential to their peace at the end of life. And when a person is able to die in peace, professionals testify that the effect is striking. '[Often] the person has slipped away in their sleep, no trauma, the environment was tranquil ... in fact, the question often is, "Have they died?" because it's that slipping away.' (Interview 5: Doctor)

Controlling pain and other symptoms

Having seen the profound effect of a person's mental state (in terms of acceptance and peace) on their dying, it is nonetheless obviously true that physical aspects of their death have a significant effect too. The experience of pain, in particular, can feature prominently in a person's experience of dying. A number of professionals mentioned the importance of being pain-free to people at the end of life. One volunteer, who worked on a palliative care ward in a Belgian hospice, quotes a Motor Neurone Disease patient for whom pain treatment had not managed to relieve all pain. 'This disease is taking hold of me ... The pain lives in me and it's dehumanizing me.'[3] This is self-evidently a central part of the debate.

There are a number of physical symptoms that clearly worry people about dying, including breathlessness, and urinary and faecal incontinence. However, the professionals we spoke to were clear that, in most instances, such symptoms could be managed. Sometimes the management of pain in a particular case depended on the sensitivity and care of the professional – usually when a person was no longer able to communicate verbally.

> *If someone is unable to tell us if they're in pain, we try and look for those non-verbal signs of pain – grimacing, rubbing of tummies, anything that might give us an idea, and if we think there is a possibility of pain, then we would give pain relief, because ... the last thing we would want is for them to have that pain.* (Interview 10: Nurse)

Some of the professionals pointed out that managing a person's pain was not the end goal, but rather a necessary step to ensuring that they could be peaceful and focus on other issues such as reflecting on their life or preparing practically for death.

> *You need to manage the pain aspects of their illness and their eventual death as best as you can. I think if you get that part*

> *right, it means there's a little bit more space emotionally or psychologically for the people ... for resolving their spiritual or psychological concerns.* (Interview 11: Nurse)

Unfortunately, and despite the importance of pain relief, it was not possible in every circumstance to ensure a completely pain-free death. Estimates range from 1.4% to 12% of people receiving palliative care dying in pain.[4] Professionals told us that even among those few people for whom this was the case, this hadn't necessarily prevented a 'good' death. That acknowledged, it is important to be realistic about the fact that a few deaths are tragically difficult for the person and those around them, where symptoms cannot be completely managed. In such cases, it becomes imperative that professionals do absolutely everything that they can to minimise the person's suffering as far as they possibly can.

> *Some deaths just aren't ever going to be good ... I guess it's making the death as good as it can be for that person, not that we can take away everything that's happening, because we can't control what the disease is doing. We're just trying to minimise the distress [for families] as much as we can.* (Interview 1: Doctor)

In an serious discussion of the complex and painful issues of assisted dying, it is important to be honest, and that means, in this instance, acknowledging the unavoidable reality of some 'bad' deaths (just as it means acknowledging the reality of ever-expanding criteria in countries that have legalised assisted dying). However, that acknowledged, it is also important to recognise that the number of these 'bad' deaths is vastly lower than the sometimes ludicrously inflated figures bandied around, and that medical science and professionals are able to do an enormous amount to ameliorate pain and suffering at the end of life.

Spiritual needs

The concepts of ‘spiritual’ and ‘religious’ needs have become increasingly distinct within care settings, such that ‘spiritual’ care is not just for ‘the religious’. Interviewees told us that many people considered religious rituals important to them as they reached the end of life.

> *There have been a few [cases], in my experience, of people who have drifted away from the church, and God, in life, and slowly through the dying process have come to realise how important that might be. So they’ve been involved in what I call reconciliation ... [that] can make a big difference to a good death for them.* (Interview 9: Chaplain)

For many people, whether they have a religion or not, it is important to plan their funeral. In some cases, making these plans was also important for the person’s peace of mind at the end of life.

> *We had one lady who, when she knew that there was no more active treatment that could be done...asked to see me. And she said, “Right, I want to plan my funeral.” So we talked round it ... and I gave her a service book and a hymn book so she could ... choose hymns and prayers and things. I ... spent a few hours with her on the Sunday, [her local vicar] came to see her on the Thursday, and she died on the Friday, because ... it was all sorted, she knew what was going to happen, her mind was at ease.* (Interview 6: Chaplain)

Spiritual and religious needs are therefore important to many people at the end of life and should not be overlooked.

Dying in a place of choice

For many people, *where* they are at the end of life is an important issue. *What's important to me* identified 'I want to be cared for and die in a place of my choice' as a key theme in people's responses to the review. Similarly, it featured prominently in our interviews with professionals, who told us that place of choice was a key concern for many of the people they had cared for.

The professionals we spoke to were clear that they would always try to meet a person's wishes around this where possible. However, it was important to be realistic about when this was not possible, or could potentially mean that the person's other needs were compromised. For instance, sometimes people want to die at home but it is difficult for them to access the care they need when there. People may therefore in some cases benefit more from being in a care home or even hospital.

> *I think if [a person's death] happens in a care home, or a hospital, you do tend to get that sense of peacefulness, tranquillity, if for no other reason than that the pain relief is there, and the nurse's presence is reassuring ... you get better deaths than people might expect.* (Interview 5: Doctor)

For many people, their desire to be in a certain place was connected to their relationships. Whilst many would want to be at home with the people they love, some are clear that they would prefer to be elsewhere if being at home would put their loved ones under excessive strain.

Some professionals highlighted how this demonstrated that, whilst the person's choice was the primary consideration, the considerations of the people who are important to them also needed to be taken into account.

Nonetheless, in those instances where a person could be at home with people who are important to them, this could make a big difference – again highlighting the important role of relationships and feeling valued. Professionals again emphasised that the people who are important to someone may or may not include family. And in some instances, those important to someone were not restricted simply to human beings.

> *These quirky things that make the news ... indicate what can be done and what can make a difference, such as the lady whose horse was brought to stick its neck through her window at the hospice, or people whose dogs come along, or that sort of thing.* (Interview 2: Doctor)

These findings demonstrate that a person's situated relationships are important to them as they approach the end of life.

Respect

A dignified death depends not just on having certain things or the presence of certain people – it also requires a certain kind of care. Compassion has been central to providing a number of the things we have seen that people ask for, from pain relief to seeing their pets. Professionals regarded the manner of care as essential for honouring the person's dignity.

For many of the professionals we spoke to, such respect was not just important when the person was aware of it. It applied, equally, to people who may not be conscious. Treating a seemingly unconscious person in this way is important partly because, as many professionals pointed out, one cannot be sure of how conscious a person is. Being unable to communicate does not necessarily mean that a person cannot understand at some level what is going on.

This is an especially important consideration when caring for people in the later stages of dementia, who may not be able to communicate but can still respond at least at an emotional level – they can feel a certain way even if they don’t fully comprehend what is being said.[5] One doctor told us about a man in the later stages of advanced dementia who was distressed, aware that his wife was dying. The man was encouraged to stroke his wife’s hand, which led to a positive change in his whole demeanour.

However, even if the person could not respond at an emotional level, it would be essential to remember that a person continues to be a person throughout the later stages of dementia and until their death. One study of the views of family carers of people with dementia reported that many participants emphasised that their relative was ‘still a person’ with a life worth living.

Similarly, it was important to continue to honour a person’s dignity even if they were clearly unconscious. As one nurse put it, ‘although there’s no communication with that person because they’re imminently dying ... you know that they were a person, and that they still are.’ (Interview 10: Nurse)

Professionals pointed out that this continues to be true after the person has died:

> *[Respect] is equally [important] after the person has died...[it] is equally important that when the person is washed, maybe got ready for the relatives to see them, that that sort of respect is carried through.* (Interview 7: Chaplain)

This is an argument also made by Michael Rosen in his *Dignity: Its History and Meaning*, mentioned earlier in this essay. Rosen argues that we should treat dead bodies with respect because we have a duty to perform acts that express our respect, irrespective of whether anyone is aware or benefiting from these acts.[6] To truly respect the dignity that is intrinsic to humanity, we must observe this respect as a duty to all human beings, regardless of whether they are alive, unconscious, or no longer living.[7]

As noted above, central to meeting all of the end of life wishes discussed is a relationship between the professional and the person approaching the end of life, in which they are regarded as valuable. It was evident throughout our interviews with professionals that they showed people they were valued:

> *It might seem like an ordinary conversation when I'm asking them things about their lives, but actually what I'm doing is trying to find out and get them to remember who they are. You know, "You're not just this patient in this bed who've got this horrible disease. You've actually had a life and you've achieved wonderful things..."* (Interview 4: Chaplain)

Through this kind of respect for the person as they approach the end of life (and during and after their death), and an emphasis on meeting their needs and wishes, care professionals can help people to have a truly dignified death. In particular, they should aim to understand and meet (as far as possible) their needs and wishes in relation to enabling them to accept their death, , relieving pain and other symptoms, enabling them to die in their place of choice where possible with the people who are important to them, meeting their spiritual or religious needs, and maintaining an attitude of respect for their personhood throughout.

However, we know that good intentions are not sufficient to enable this to be the case. Currently, palliative care in England is unequal, understaffed and under-resourced,[8] with much-needed hospice staff being made redundant as a result.[9] Without proper investment and support, including a well-staffed workforce who feel valued and not burnt out, and who have the resources they need to consistently provide the standard of care they wish to deliver, too many people tragically die without dignity. Ultimately, the key to a truly dignified death is not the legalisation of assisted dying but a well-funded, staffed and run system of palliative care.

---

1 Choice in End of Life Programme Board, *What's important to me: A Review of Choice in End of Life Care*, *www.gov.uk/government/publications/choice-in-end-of-life-care*, accessed 14 May 2017.

2 Caroline Richmond, 'Dame Cicely Saunders', *BMJ* 331:7510 (2005), p. 238.

3 Attilio Stajano, *Only Love Remains: Lessons from the Dying on the Meaning of Life – Euthanasia or Palliative Care?* (W. Sussex: Clairview Books, 2015), p. 40.

4 Zamora, B., Cookson, G. and Garau, M. (2019) Unrelieved Pain in Palliative Care in England, OHE Consulting Report, London: Office of Health Economics. Available at: https://www.ohe.org/publications/unrelieved-pain-palliative-care-england (accessed 10 April 2024).

5 Alzheimer's Society, 'The later stages of dementia', Factsheet 417 (2012).

6 Rosen, *Dignity*, pp. 139-40.

7 Rosen, *Dignity*, p. 160.

8 Mahase E. 'Palliative and end-of-life care in England is "variable and inequitable,"' report finds *BMJ* 2023; 382 :p1635 doi:10.1136/bmj.p1635, accessed 13 Oct 2024.

9 Church, E. 'Hospice to lay off dozens of staff amid palliative care funding crisis', *Nursing Times,* 28 June 2024. https://www.nursingtimes.net/news/workforce/hospice-to-lay-off-dozens-of-staff-amid-palliative-care-funding-crisis-28-06-2024/, accessed 13 Oct 2024.

6

Conclusion

With the prospect of assisted dying becoming legal in England and Wales, it is essential to critically analyse both the change that is being proposed, and the key term underpinning the argument for doing so – 'dignity'.

The way in which dignity is often used in this context – grounded in the idea of autonomy and independence, expressed most fully in the ability to choose when and how to die – is appealing but ultimately deceptive. Philosophically speaking, grounding dignity in autonomy fails to account for significant groups in society, including those with learning disabilities or advanced dementia – many of whom have been affected by assisted dying legislation elsewhere. Extreme cases show that simply equating a free and informed choice with the right thing to do is a false move.

Moreover, practically, once dignity has been equated with choice, it becomes difficult to justify limiting assisted dying to those with terminal illnesses. As we have seen in Canada, expanding assisted dying laws beyond terminal conditions is a natural consequence of this understanding. The criterion of "unbearable suffering" can be very broadly applied – extending to those with chronic but non-terminal physical health conditions, disabilities and even potentially mental health conditions.

In contrast to this approach, we have proposed an understanding of dignity that is rooted in intrinsic, relational worth: humans are inherently valued and loved. In Christian thought, this is understood in terms of being created in the 'imago Dei' and the permanent loving attention of God. However, many people, regardless of religious faith, intuitively hold the belief that people have intrinsic worth, one that can't be diminished by circumstance or even subjective belief.

Not only is this understanding, we believe, philosophically more persuasive and robust, but it has very different practical implications. When faced with requests for assisted dying, the focus shifts to demonstrating love and affirming the person's value. When a person is suffering, professionals and those around the person have a number of options to alleviate it without prematurely ending their life. And crucially, when a person is requesting it out of fear of being a burden, it must be communicated to them that they are inherently valued, loved, and worthy of being alive and supported. Or alternatively, we should remember that everyone is a burden to someone else at some point in their life – that is simply the nature of being human, and not a problem. We are called to bear one another's burdens.

> **We should remember that everyone is a burden to someone else at some point in their life – that is simply the nature of being human, and not a problem. We are called to bear one another's burdens.**

This understanding is crucial. We have already noted the fears that many people with disabilities have about legalisation of assisted dying, and the message it could send that people are an unacceptable burden on society with lives not worth living. Many older people, especially since the Covid pandemic, may also fear this to be the case. In a qualitative study of the views of older people on assisted dying, one participant said:

> *Where's the dividing line between the next step, where Big Brother comes along and says, "Well, okay ... very few people over the age of X, let's call it 90, really make a valuable contribution to society; they take up space and they're a demand and even a drain on the health system; we keep on patching them up but*

> *they're going to die in a few years' time anyway and that's a waste of money, so let's knock 'em." Where's the dividing line?* [1]

This is lamentable, but sadly may not come as a surprise. We have already seen that people fear being seen as or made to feel that they are a burden, and we have noted the views of commentators such as Matthew Parris and Baroness Warnock. To change the law in a way that potentially leads to an expansion in people choosing to end their own lives rather than be cared for at a cost to others would therefore risk an unequivocal violation of the principles of human dignity that we have espoused.

As a society, we have an opportunity to send a clear message to those who are approaching the end of life that they are valued and worthy of love and care. This requires citizens, the media, health and care organisations, and policymakers to work collectively to advocate for proper investment in end of life care staff and resources, for fixing the many gaps in the health and care system, and tackling systemic inequalities that mean that those in deprived areas have less access to good quality care.

This vision of society – where people are supported to live with dignity until the end of their lives – is surely preferable to one in which the solution is intervening to end people's lives. While assisted dying may appear more economically efficient and to empower those with means to make this choice independently, it would risk the safety of the vulnerable, including those affected by inequalities, and even facing possible coercion. Ultimately, it reinforces the damaging message that a person reliant on others for care and support is not unconditionally valuable, and would therefore fail truly to honour the dignity they should be accorded as a human being.

---

[1] Phillipa J Malpas et al, ‘Why do older people oppose physician-assisted dying? A qualitative study’ *Palliative Medicine* 28:4 (2014), p. 356.

Theos – enriching conversations

Theos exists to enrich the conversation about the role of faith in society.

Religion and faith have become key public issues in this century, nationally and globally. As our society grows more religiously diverse, we must grapple with religion as a significant force in public life. All too often, though, opinions in this area are reactionary or ill informed.

We exist to change this

We want to help people move beyond common misconceptions about faith and religion, behind the headlines and beneath the surface. Our rigorous approach gives us the ability to express informed views with confidence and clarity.

As the UK's leading religion and society think tank, we reach millions of people with our ideas. Through our reports, events and media commentary, we influence today's influencers and decision makers. According to *The Economist*, we're "an organisation that demands attention". We believe Christianity can contribute to the common good and that faith, given space in the public square, will help the UK to flourish.

Will you partner with us?

Theos receives no government, corporate or denominational funding. We rely on donations from individuals and organisations to continue our vital work. Please consider signing up as a Theos Friend or Associate or making a one off donation today.

Theos Friends and Students

- Stay up to date with our monthly newsletter
- Receive (free) printed copies of our reports
- Get free tickets to all our events

£75/ year
for Friends

£40/ year
for Students

Theos Associates

- Stay up to date with our monthly newsletter
- Receive (free) printed copies of our reports
- Get free tickets to all our events
- Get invites to private events with the Theos team and other Theos Associates

£375/ year

Sign up on our website:
www.theosthinktank.co.uk/about/support-us

Other Theos publications include:

AI and the Afterlife: From Digital Mourning to Mind Uploading
Nathan Mladin

More: The problem with productivity
Nick Spencer, Hannah Rich and Nathan Mladin

Love, Grief, and Hope: Emotional responses to death and dying in the UK
Madeleine Pennington

Love's Labours: Good work, care work and a mutual economy
Hannah Rich

Ashes to Ashes: Beliefs, Trends, and Practices in Dying, Death, and the Afterlife?
Marianne Rozario

Working Five to Nine: How we can deliver work–life integration
Paul Bickley

Dignity at the End of Life: What's Beneath the Assisted Dying Debate?
Andrew Grey

The Ties That Bind: The rise of insecure and lone working and the search for mutual bonds
Tim Thorlby

The Meaning of Dignity

The question of assisted dying is never far away and is now back somewhere near the top of the political agenda. It's a serious and sensitive debate, about which well-meaning people can disagree profoundly.

Much of that disagreement can be traced to conflicting ideas about the meaning of human 'dignity'. 'Dignity' is used in two subtly different ways – one to do with autonomy and choice, the other with care and relationships – and how we understand the term shapes how we think people should be treated at the end of life.

This essay explores both meanings and argues that the idea of 'dignity-through-care' gives a better account of what it means to be human. More worryingly, it argues that if dignity is understood as personal autonomy expressed through choice, society no longer has any deep reason to deny an individual their choice to die, even if they are not in a terminal condition, not in unbearable pain, or indeed not even in physical ill-health.

Andrew Grey has BA and MPhil degrees in theology and ethics from the University of Oxford. He has over 10 years' experience in the health and care sector, primarily dealing with life-limiting conditions.

Images: Emily Ikoshi

ISBN: 978-0-56-403903-6

'THEOS'

9 780564 039036 >