THE TERMINALLY ILL ADULTS (END OF LIFE) BILL 2024

A MEDICAL AND ETHICAL PERSPECTIVE

John Wyatt

NOVEMBER 2024

John Wyatt is Emeritus Professor of Neonatal Paediatrics at University College London (UCL). He was a front-line NHS consultant neonatologist in central London for more than 25 years, with particular expertise in brain injury and neonatal palliative care. He led an internationally recognised multidisciplinary research group at UCL and pioneered new protective treatments for brain-injured babies. He is a Council member of the Medical Defence Union and current President of the Christian Medical Fellowship. He has been a member of regional and national clinical and research ethics committees and continues to teach medical ethics at undergraduate and postgraduate levels. The views expressed in this report are entirely personal and he is not acting as a representative of any organisation.

Design: Dave Potter david-potter.co.uk

Contents

FOREWORD

Baroness Grey-Thompson DBE

On 29 November 2024, the House of Commons will debate the question of assisted suicide. The last time this issue came to the Commons, it was met with overwhelming rejection, by a majority of more than 200 votes. As the question is put before them again, with the Bill in the form of a Private Members' Bill, it remains a highly emotive and complex issue, and the gravity of the subject demands both thorough research and educated debate.

Professor John Wyatt, a doctor, author, speaker and research scientist, presents an astute argument on assisted suicide. A consultant of nearly 30 years in the NHS, he has invaluable experience gained from working with neonatal palliative care patients, which led him to do pioneering work on protective treatments for brain-injured babies. Now retired, he focusses on the ethical and philosophical issues raised by advances in medical science and technology.

Professor Wyatt's research, succinctly laid out in this report, highlights many of the present issues and possible consequences of legalising assisted suicide. Starting with a clear explanation of the key terms used when debating this topic, Professor Wyatt continues by discussing the possible problems that would arise if this Bill were to be legalised. He then delves into real-world problems to show the impact of assisted suicide, both intended and unintended. Having set out the issues of 'suffering' which is so often referred to as a reason to change the law, he concludes on a hopeful note: a call for expert palliative care. Professor Wyatt's report provides a comprehensive guide to the realities of assisted suicide.

As a Paralympian and Parliamentarian, my position has offered me a level of protection and support that many disabled people do not have. It is important to not forget the constant societal pressures and exclusion that people face because of their impairment and the inequality they face across all areas of their lives, including when engaging with our health and social care system. This legislation will only exacerbate the pressures on disabled people and the underlying assumption that their lives are worth less. Legalised assisted suicide is not a choice if the alternative is insufficient care and lack of autonomy. A compassionate society is not one which suggests death when palliative care is failing so many.

Therefore, I urge Parliamentarians and the public to read this report and consider this topic. What may sound like easy sound bites are not so simple when the detail behind them is examined. This report provides a balanced reflection on the wider consequences that this law would have on our citizens and society as a whole. The proposed legislation is not only lacking necessary safeguards but would irrevocably change how our society views disabled people, those who are considered vulnerable, and older people. The careful scrutiny of a proposed legislative change, especially one of this significance, has never been so important. This report will undoubtedly help in this process.

Executive Summary

The Terminally Ill Adults (End of Life) Bill 2024 introduced by Kim Leadbeater MP is an opportunity for a national conversation about how we want to treat those at the end of life and how we approach death and dying.

My personal view, based on 40 years' experience as a practising physician, NHS consultant and specialist in medical ethics, is that this Bill is the wrong approach and that there is a better way to give individuals and their families dignity at the end of life.

The Leadbeater Bill would fundamentally change the societal relationship with the medical profession because it would allow a doctor to assist an informed competent, terminally ill adult to end their life through self-administration of lethal substances. For the first time we would be saying that act of assisting a suicide should be exempt from prosecution. 'Assisted dying' sounds positive, compassionate and uncontroversial, but we would be endorsing a long term change in the role of doctors in our society, from healers to active participants in ending their patient's life.

Of course, we all want to be treated compassionately during and at the end of our lives. Those campaigning for this Bill believe it is the compassionate response to suffering – even though a person's suffering is not a criteria for eligibility in this Bill, as it is in other jurisdictions. Campaigners say only those who want to will exercise the choice for an assisted suicide but, by definition, this 'choice' will only be available to those terminally ill with less than six months to live. If we want to argue that this Bill is needed to relieve suffering, there is a logical argument to extend the 'choice' under this Bill to others who are chronically sick, disabled or suffering with poor mental health.

Public polling suggests support for this legislation but most palliative care doctors, who are the experts in caring for people at the end of their lives, are against a change in the law. This Bill is being debated in the context of public policies to reduce suicides, defend the rights of those with disabilities and care for an aging population with increasing chronic needs who are concerned about being a burden to their families and the NHS/social care. If this Bill passes, we can expect to see the option of assisted suicide become a regular 'treatment option' in the NHS . We need to recognise that our choices are also governed by the wider environment we live in so the 'choice' to die will always be influenced by our circumstances and the explicit and implicit views of those around us. We cannot legislate for these subtle pressures.

There are also practical concerns about the implementation of this Bill from difficulties of determining prognosis, use of drugs not licensed or tested for this purpose, potential complications of ingesting lethal substances, negative impact on the medical profession, abuse by relatives and the potential for incremental change to make the Bill's application much wider.

Based on the experience of other jurisdictions, we can expect to see what are originally defined as 'safeguards' becoming seen as 'barriers to access' and widening of the criteria beyond terminal illness through repeated court cases. In Canada, following repeated legal challenges, the law expanded in less than 5 years to cover individuals with other conditions whose death is not reasonably foreseeable and is due to be extended again to people with mental illness in the near future. Sadly, there are numerous reports of individuals choosing to die under the Canadian law because of inadequate social care.

It has been argued that there will always be cases that palliative care is powerless to assist. But this is highly misleading. Given the complex and multifaceted nature of suffering at the end of life, it is not possible for expert carers to fix all broken relationships, cure loneliness or solve existential angst. Palliative care is not a magic wand that fixes every problem, but in my personal clinical practice I have observed time and again that with expert care apparently intractable suffering can be ameliorated and controlled.

Indeed, the UK is an international leader in palliative care, which is effective at addressing physical, emotional, relational and existential suffering. However, palliative care requires a trained and skilled professional workforce, properly funded and resourced to care for the many individuals who die in uncontrollable pain and without adequate care. Palliative care represents a tiny fraction of total NHS spending. It surprises many that currently hospices receive only one third of their funding from the Government and rely on local fundraising to provide vital care to people.

If we wish to tackle suffering and distress at the end of life, our main priority should be to enable all terminally ill people in the UK to have access to high-quality and adequately resourced palliative care. Surely it is right to fix the funding crisis and make excellent care our overriding goal before we contemplate legalising medically assisted suicide.

CHAPTER 1:

The Terminally Ill Adults (End of Life) Bill 2024

Key Points: *The Leadbeater Bill would allow a doctor who assists an informed competent, terminally ill adult to end their life through self-administration of lethal medication, to be exempt from prosecution. Eligibility for assistance does not depend on suffering unlike other jurisdictions.*

Kim Leadbeater MP introduced the Terminally Ill Adults (End of Life) Bill to the House of Commons on 16 October 2024 and the Bill was published on 11 November 2024.[1] The intention of the Bill is that lethal medication can legally be provided by a doctor to an adult to end their life. A formal debate on the Bill is due to take place in the House of Commons on 29 November 2024.

What does the Bill do?

To be eligible for an assisted suicide, an adult will have to demonstrate that they:

a) have a clear, settled and informed wish to end their own life made without coercion;

b) have legal capacity to make the decision to end their own life;

c) have been diagnosed by a doctor as having an inevitably progressive illness, disease or medical condition which cannot be reversed by treatment (which is defined as "a terminal illness"); and as a consequence of that terminal illness, are reasonably expected to die within six months; and

d) be a resident of England and Wales for at least 12 months and being registered with a GP practice in England and Wales (clauses 1 and 2)

It provides an apparently clear legal framework in which medical and legal professionals can operate. Two independent doctors must independently examine the patient and certify their agreement that the individual has a limited life expectancy of less than 6 months, a "clear and settled wish to end their own life" and that they are not subject to any form of coercion or duress. (clauses 1 and 2)

The Bill stipulates that in deciding whether to countersign a declaration, the two doctors "must be satisfied that the person making it has been fully informed of the palliative, hospice and other care which is available to that person." (clause 9)

There is a provision to seek specialised psychiatric help: if either of the two doctors has any doubt about the individual's capacity to make a legally-valid decision, the doctor must refer the person for an assessment by a specialist in psychiatry, and must "take account of any opinion provided". (clause 9)

The High Court must provide additional scrutiny to confirm that the provisions of the proposed law have been satisfied. (clause 12).

Although the doctor may assist the person by preparing medication and medical devices for administration of the drugs, the Bill does not authorise a doctor to administer a medicine to another person "with the intention of causing that person's death." The final act must be the patient's alone. (clause 18)

---

[1] Terminally Ill Adults (End of Life) Bill

Finally the Bill states that the doctor must remain with the person until the person has self-administered the medicine and died, or decided not to self-administer the medicine.

With regard to conscientious objection the Bill states, no doctor or other health professional "is under any duty (whether by contract or arising from any statutory or other legal requirement) to participate in the provision of assistance in accordance with this Act." (clause 23)

So, in summary, the Bill attempts to balance the settled desire of an individual who has limited life expectancy to end their life, against the need to ensure that they have appropriate legal capacity, that they are not under any coercion or pressure, and that they are aware of alternatives such as palliative care. The instruction that the doctor must not directly administer lethal medication, even if requested, is clearly intended to safeguard the patient's autonomy by insisting that the patient alone must be responsible for self-administering medication that will end their life.

Before I turn to some of the practical and ethical problems with the Bill let's consider its underlying assumptions and philosophy.

The Bill's underlying assumptions and philosophy.

The clear intention of the Bill is to enable lethal medication to be prescribed so that certain specified individuals can end their own lives. The sole purpose of any medication prescribed and administered under the Bill is to end a person's life swiftly and cleanly, although this does not always happen in practice. In any other context the action of the person in knowingly taking lethal medicine would be described as committing suicide and the actions of the doctor in prescribing and supplying lethal medication would be described as assisting a suicide. If a doctor was to provide their patient with a gun and the patient used the gun to kill themselves, the doctor would be prosecuted for assisting a suicide. According to current English and Welsh law, the Suicide Act 1961, intentionally assisting someone to end their life is a serious criminal offence, with a penalty of up to 14 years' imprisonment. But the underlying philosophy of the Leadbeater Bill is that there is such a thing as a suicide which is both rational and legally justified. Indeed, the Bill specifies that any person who acts under the provision of the Bill would be immune from prosecution under the Suicide Act 1961.

Is the Leadbeater Bill intended to stop suffering?

It is immediately obvious that the Bill makes no mention of 'suffering'. It is not necessary for the person who wishes to kill themselves to exhibit any degree of pain, distress or suffering before being eligible for medically assisted suicide. This is in stark contrast to similar legislation in Netherlands, where an essential criterion is 'hopeless and unbearable suffering',[2] or in Canada where a person must have 'enduring and intolerable physical or psychological suffering that cannot be alleviated under conditions the person considers acceptable.'[3]

In a recent article in The Guardian newspaper, Kim Leadbeater MP wrote about the "heartbreaking lack of choice for those who know that an unbearable and painful death may lay ahead".[4] Former MP, Paul Blomfield, now Chair of campaigning organisation Dignity in Dying, wrote a supportive piece entitled "It's time to end the suffering and offer choice at the end of life".[5] But 'suffering' is nowhere mentioned in the wording of the Bill. In order to be eligible for assisted suicide under the legislation, it is not necessary for the person to give any reason as to why they wish to end their life. They simply have to demonstrate a 'settled wish'.

---

[2] https://www.government.nl/topics/euthanasia/euthanasia-assisted-suicide-and-non-resuscitation-on-request

[3] https://www.canada.ca/en/health-canada/services/medical-assistance-dying.html#a1

[4] https://www.theguardian.com/commentisfree/2024/oct/03/assisted-dying-bill-parliament-kim-leadbeater-labour-mp

[5] https://www.government.nl/topics/euthanasia/euthanasia-assisted-suicide-and-non-resuscitation-on-request

So the legislation for England and Wales is based on the presumption that the suicide of a person with limited life expectancy of less than 6 months should be supported and legally and medically facilitated whatever the motivation, provided that person has legal capacity and is 'un-coerced'.

For comparison it is worth looking at analogous legislation, the Medical Assistance in Dying law in Canada, where in order to be eligible for "medical aid in dying" (which covers both euthanasia and assisted suicide), all three of the following criteria must be fulfilled:

i) have a serious and incurable illness, disease or disability,

ii) be in an advanced state of irreversible decline in capability, and

iii) have enduring and intolerable physical or psychological suffering that cannot be alleviated under conditions the person considers acceptable.

None of these criteria are required according to the Leadbeater Bill. The only medical requirement is a terminal illness with a life expectancy of less than 6 months.

Problems with the underlying rationale of the Bill

If the real motivation is to limit 'intolerable suffering', as many campaigners have stated, then why should limited life expectancy of less than 6 months be a legally acceptable reason for suicide, whilst 'unbearable suffering' is not?

Surely it can be argued that the suffering of someone with a progressive medical condition who has a year or more to live is greater and more worthy of our compassion than someone who is pain-free and has only a few months to live. It seems strange to condemn people suffering a painful and progressive condition to years of hopeless and unbearable suffering if they are unable to get suitable relief, whereas the terminally ill person who is pain-free is eligible to receive life-terminating medication? On what rational ground can that be defended?

But there's another problem as well. Suppose the legislation has been passed by Parliament and is now in force. Here is a person with an advanced and painful neurological condition who wishes to end their life. They are assessed by a doctor and a decision is made that they are eligible for lethal medication under the Act. The High Court agrees. However, during the reflection period of 14 days after the High Court's declaration and before the second declaration, their mental condition deteriorates and they are judged to have lost sufficient legal capacity. According to the Bill it would be illegal to go ahead with the assisted suicide even if the person is pleading to be killed. So, if the supporters of the Bill are concerned about 'stopping unbearable suffering', why is there no provision to end the lives of those who, though suffering terribly, have lost their legal capacity because of their illness?

CHAPTER 2:

The beginning of wisdom is to call things by their proper names

__Key Points:__ Language matters. The role of doctors has been healing not the deliberate ending of life. 'Assisted dying' sounds positive, compassionate and uncontroversial but it encompasses euthanasia and assisted suicide, that is the intentional medical killing by act or omission, as part of medical care. In cases of euthanasia, a doctor gives a person lethal substances directly. In an assisted suicide the doctor prescribes and sometimes prepare lethal substances, but the person themselves does the final act of taking the lethal mixture.

"When I use a word," Humpty Dumpty said, in rather a scornful tone, "it means just what I choose it to mean—neither more nor less." From 'Alice in Wonderland', Lewis Carroll

In previous attempts at legislation, campaigners adopted the phrase 'assisted dying' for the act of prescribing and administering lethal substances with the intention that a person should end their own life. This is the phrase that is used by the campaigning organisation Dignity in Dying. But the Leadbeater Bill uses the anodyne terminology Terminally Ill Adults (End of Life) Bill.

'Assisted dying' sounds positive, compassionate and uncontroversial. Yet what the Leadbeater Bill is describing is not the normal, skilled and compassionate care of those dying, which is already a major part of healthcare across the country, but the intentional planning, preparation and direct assistance of a suicide, which up to now has been a serious criminal offence under the Suicide Act.

The messiness, uncertainties, emotional charge and grisly details of the life-exterminating process seem to be carefully air-brushed. As philosopher Kathleen Stock put it, "At times, it can sound as if one is being offered a particularly relaxing spa treatment. With a pleasing ring of supportiveness, you are now being "assisted" in achieving something, rather than being killed by a doctor or killing yourself."[6]

It is not surprising that many health professionals who do in reality assist dying people at the end of life have complained about the deliberate hijacking of this phrase to mean a completely different activity.

In the Netherlands, the official government language for the procedure is 'assisted suicide'.[7] In Belgium, the term 'euthanasia' is used for both lethal injection and what is technically medically assisted suicide. It is interesting to reflect on why those who framed the Terminally Ill Adults (End of Life) Bill, including eminent lawyers whose careers have depended on the extremely precise and forensic use of language, are so committed to using this ambiguous terminology, avoiding the much clearer term "assisted suicide".

The Dignity in Dying website defends the distinction between 'assisted dying' and 'assisted suicide'. "Dying people who want to control the manner and timing of their deaths are not suicidal. Laws which permit assistance for people who are not dying to take their lives are usually referred to as 'assisted suicide laws'. This is beyond the scope of what Dignity in Dying campaigns for."[8]

But this is surely playing with words. No reputable philosopher, ethicist or legal expert could defend this distinction. The legal definition of suicide is "the act of intentionally ending one's own life", this is the act

---

[6] https://unherd.com/2024/04/the-assisted-dying-lobby-has-already-won

[7] Euthanasia, assisted suicide and non-resuscitation on request in the Netherlands | Euthanasia | Government.nl

[8] https://www.dignityindying.org.uk/assisted-dying/key-questions/ accessed 2 November 2024

which is controlled by the Suicide Act 1961, and this is the act which the Bill is designed to legalise under certain circumstances.

The argument over terminology is a sign of how important language is in the way we as human beings assess the morality of our actions. The words we use to describe our own actions, and the actions of others, matter. Those who are campaigning for a change in the law are well aware that many people in our society have deep intuitive moral concerns about legalised killing and suicide. As a doctor if I describe my own actions as "assisting a dying person", I am more likely to conclude that it is morally acceptable compared with "helping someone to commit suicide".

But clarity of moral thinking depends on clarity of language. As an ancient proverb puts it, "The beginning of wisdom is to call things by their proper names".

Defining euthanasia and assisted suicide

A widely accepted definition of euthanasia is "The intentional medical killing by act or omission, as part of medical care."

Note first the emphasis on intentional killing, a deliberate and premeditated act to end a life. Even if a person has a terminal illness, the intention is that death should occur at a specified time using lethal drugs. In fact, the intention to kill is revealed in the choice of drugs used by doctors in the Netherlands, Canada and elsewhere for euthanasia. The most common drugs employed are barbiturates in extremely high dosage, often coupled with an intravenous muscle relaxant drug designed to stop respirations instantaneously. These drugs are those of the anaesthetist: they are totally different from those used in palliative care.

In palliative care, the intention of the doctor is to use drugs that control symptoms of pain and distress but not to hasten death. Pain relief has become a sophisticated science in palliative care and it is nearly always possible to achieve effective symptom relief without hastening death. In fact, only drugs that do not carry a serious risk of killing are used. But in euthanasia different drugs are chosen. They have one intention only - to induce death rapidly and 'cleanly'. The intentions of the doctor are revealed in the choice of drugs. To refer to this as 'assisting the dying process' is to stretch language to breaking point.

Note that euthanasia, intentional killing, is not the same as withdrawing or withholding medical treatment that can bring no benefit or that is excessively burdensome to the patient. This has been universally regarded as good medical practice for hundreds of years and both law courts and medical ethicists have remained clear that this is not morally or legally equivalent to intentional killing. (In the past, the terms 'active euthanasia' and 'passive euthanasia' were widely used, but most ethicists now agree that they are ambiguous and should be dropped).

Assisted suicide

Medically assisted suicide, as framed in the Leadbeater Bill, is practically and morally very closely related to euthanasia: the intention of the doctor is that the patient should die rapidly and 'cleanly'. In the USA there has been a recent move for doctors to employ an experimental and completely unlicensed combination of massive doses of a cardiac drug, digoxin, combined with a mixture of sedatives and painkillers.[9] The drugs are often taken together with an anti-emetic drug to prevent vomiting.

The doctor obtains the lethal drugs, gives them to the patient and gives detailed instructions on how the drug should be taken to try to ensure that death occurs rapidly and without complications. The patient must be instructed to remain upright after swallowing the lethal mixture to reduce the risk of vomiting and inhalation. In cases where the patient is unable to take the drug orally, the doctor may prepare a mechanism

---

[9] Oregon, Death with Dignity Act, 2023 Data Summary, https://www.oregon.gov/oha/PH/PROVIDERPARTNERRESOURCES/EVALUATIONRESEARCH/DEATHWITHDIGNITYACT/Documents/year26.pdf

for the drugs to be administered artificially, including inserting an intravenous line and obtaining and drawing up the drugs into an automated device, although the patient must make the final decision by pressing a button.

Throughout this process the actions of the doctor are intended to end the life of the patient, to introduce death. The doctor has implicitly agreed with the patient's opinion that their death is preferable to further living. But the doctor hangs back from the final step. The patient must swallow the mixture or press the button. Is there any real moral difference between this and the doctor taking the final lethal action? Inevitably the doctor is actively engaged and morally complicit in the self-destruction of the patient's life.

But yes, you may say. Assisting suicide is not the normal role of doctors but there are over-riding principles and arguments that justify these actions in extreme circumstances. Here is a patient who knows that death is inevitable within 6 months and they wish to end their own life painlessly with medical help. Surely the doctor should be legally allowed to assist their suicide, motivated by genuine compassion for the plight of the patient. In the next two chapters we look at the principal arguments in favour of the legislation – the argument from compassion and the argument for the right to choose or 'autonomy'.

CHAPTER 3:

Compassion

***Key Points:** We all want to be treated compassionately. Those campaigning for this Bill believe it is the compassionate response to suffering – even though suffering is not a criteria in the Bill. Modern palliative care is effective at addressing physical, emotional and relational needs but requires a trained and skilled professional workforce which are properly funded to ensure individuals do not die in uncontrollable pain.*

As we try to assess the arguments for and against the Leadbeater Bill, it's important to recognise the noble and humane motives that drive many campaigners to fight for a change in the law, including, no doubt, Kim Leadbeater. The campaigners are motivated by the number of people in our society who die in distress, frightened, in pain, and without adequate support and skilled care. A small number of desperate individuals are driven either to take their lives here or to travel out of the country in order to end their lives. Surely these people deserve our compassion and understanding? Isn't it better to help people to end their own lives than to face the horrific prospect of agonising and uncontrollable pain and distress?

Esther Rantzen echoes these sentiments, writing "Isn't it typically British that we give the pets we love a pain-free, dignified, private death but we can't offer it to the people we love."[10]

A son whose terminally ill father tragically killed himself with a shotgun said, "People shouldn't have to do what my dad did. But he was in a world of pain and it was only going to get worse. My dad decided to put himself down...We need more compassion."[11]

At first glance the argument from compassion seems so simple and compelling. Of course, common humanity does indeed tell us that we do have a duty to respond to those who are suffering. Yes, we should as a society respond to the pain and distress of terminally ill patients. But is helping suicidal people to kill themselves the best practical and most compassionate response that is available? Can't practical compassion drive us instead to the provision of expert pain relief, psychological support, and human companionship through the terminal phases of illness?

Understanding suffering at the end of life

Most people imagine that people who are suffering because of a terminal illness have terrible and uncontrollable physical pain, like the terrible pain of a broken leg or peritonitis. But this is a dangerous misunderstanding. In reality, this kind of physical pain is medically straightforward to control. Doctors have available a panoply of powerful and effective painkillers and nobody needs to fear uncontrollable physical pain at the end of life. But the suffering which many people experience is not primarily physical. It is the result of deep psychological, relational and spiritual issues. As we shall see in a later chapter, one of the remarkable discoveries of modern palliative care was that with skilled and dedicated care it is possible to control not only physical pain, but also address the psychological pain, relational pain and spiritual pain so often experienced by dying people. As Cicely Saunders, the remarkable pioneer of palliative care, put it, "You don't have to kill the patient in order to kill the pain".

It has been argued that there will always be cases that palliative care is powerless to assist. But again this is highly misleading. Given the complex and multifaceted nature of suffering at the end of life, it is not possible for expert carers to fix all broken relationships, cure loneliness or solve existential angst. How could this

---

[10] https://www.bbc.co.uk/news/uk-politics-68919386

[11] https://www.theguardian.com/society/2024/feb/29/we-need-more-compassion-call-for-assisted-dying-reform-as-uk-mps-report

possibly be the case? Palliative care is not a magic wand that fixes every problem, but I have observed time and again that with expert care apparently intractable suffering can be ameliorated and controlled.

Stopping the suffering

As we have already seen, in other countries such as the Netherlands and Canada, the legislation which permits medical assistance with death insists that severe suffering must be present. It is not unusual in the Netherlands for a patient's request for euthanasia to be turned down by their doctor because he or she did not consider that the patient's suffering was genuinely 'hopeless and unbearable'. The implication in the Netherlands is that even if a patient pleads to be killed, medical destruction of that life is not morally justified unless a threshold of suffering is reached.

So to put it rather bluntly, medical killing is only justified in the Netherlands and Canada if the doctor determines there is 'severe suffering', but there is no requirement to be terminally ill. But for England and Wales, it is proposed that medically assisted suicide can be carried out if there is terminal illness, but there is no legal requirement to prove that you are suffering. The incompatibility of the different legal frameworks is troubling and seems to indicate a level of arbitrariness and inconsistency in the legal grounds for assisting suicide.

There is a tendency for those in favour of the Bill to use highly emotive language, implying that every moment thousands of people are dying in terrible distress – 'suffering terrible deaths', 'writhing in agony'. But this is very misleading. Sadly, at the moment, in the UK and elsewhere across the world, the provision of high-quality palliative care is patchy and inadequate. In 2023, it was reported that "People dying in hospitals have significant and poorly identified unmet needs"[12] and "palliative and end of life care services in England is variable and inequitable…unable to consistently provide what people have been led to expect."[13]

So yes, the uncomfortable truth is that many people in the UK do die in pain and distress. But those of us who have had the privilege of caring medically for many people at the end of life know that this is not inevitable. Pain and distress can be remarkably ameliorated at the end of life, but it takes clinical skill, training and substantial resources. However, Hospice UK has estimated that as many as one in four people in the UK are not able to access the palliative and end of life care services and support needed.[14] Which is better for society as a whole, to focus on improving expert and compassionate care for suffering people or to legalise suicide as a way out?

---

[12] Tavabie S, Ta Y, Stewart E, et al, Seeking Excellence in End of Life Care UK (SEECare UK): a UK multi-centred service evaluation BMJ Supportive & Palliative Care, Published Online First: 11 July 2023. doi: 10.1136/spcare-2023-004177

[13] Variations in adult palliative care services (hsib.org.uk) and https://www.hsib.org.uk/documents/435/hsib-report-variations-in-the-delivery-of-palliative-care-services-to-adults.pdf

[14] Equality in hospice and end of life care: challenges and change, Hospice UK, Page 6, 2021

CHAPTER 4:

The right to choose

***Key Points:** Campaigners say only those who want to will exercise the choice for an assisted suicide but, by definition, this 'choice' will only be available to those terminally ill with less than six months to live. We need to recognise that our choices are also governed by the wider environment we live in so the 'choice' to die will always be influenced by our circumstances and the explicit and implicit views of family and friends around us. Depression associated with terminal illness can also influence choices. If this Bill passes, we can expect to see the option of assisted suicide become a regular 'treatment option' in the NHS.*

"I believe passionately that any individual should have the right to choose, as far as it is possible, the time and the conditions of their death. I think it's time we learned to be as good at dying as we are at living." Terry Pratchett[15]

On the surface it seems so simple. Human beings have the right to choose – end of story. If we can control every other aspect of our lives, such as where we live, how we spend our money, how we spend our time, then why on earth cannot we choose how and when we end our own lives?

Philosophers call this the principle of autonomy, a word derived from the Greek auto-nomos, meaning self-rule, or more crudely, 'I make my own laws'. Autonomy is the principle behind patient choice. It is enshrined in the Patient Charter, the NHS Constitution, the Mental Capacity Act and in General Medical Council guidelines for doctors. It is the patient who should be at the centre, choosing and controlling what treatment should be given. And given that we have the right to make choices about every other aspect of our medical treatment, why do we not have the right of self-rule when it comes to when and how we die?

Here's philosopher AC Grayling: "I believe that decisions about the timing and manner of death belong to the individual as a human right. I believe it is wrong to withhold medical methods of terminating life painlessly and swiftly when an individual has a rational and clear-minded sustained wish to end his or her life."[16]

There is no doubt that respect for individual autonomy is a fundamental principle of modern medical and legal practice. English judges have repeatedly ruled that patients with legal capacity have an absolute right to refuse life-sustaining treatment, even if death becomes inevitable, whatever their motivation. But should the same respect for autonomy lead to a conclusion that there should be a legal right for patients to kill themselves?

Choice is not as simple as it sounds

As we saw at the beginning of the chapter, the author Terry Pratchett argued that everybody had the right to control the time and manner of their death. But this is not as simple as it sounds. Was Terry Pratchett really arguing that we should assist people to destroy their own lives under any circumstances and for any reason whatsoever? Would we wish to belong to a society that assisted suicidal people to kill themselves whenever they wished? Or to a society that provided humane methods for self-destruction, that made suicide an easy process for lonely, elderly, disabled or despairing people?

---

[15] Quotation from Dignity in Dying website, https://www.dignityindying.org.uk

[16] https://humanists.uk/about/our-people/patrons/professor-a-c-grayling/

Of course, the Leadbeater Bill would not legalise assisting a suicide in any circumstances, even if the person had legal capacity. So, the principle of personal choice or autonomy is severely restricted by the proposed Bill, and those restrictions appear uncomfortably arbitrary. Why should an 18-year-old be able to exercise a choice to kill themselves but not a 17-year-old who was in an identical predicament? In other areas of English medical law it has been agreed that adolescents as young as 13 and 14 are capable of making autonomous decisions about their treatment without the agreement of their parents. Why should terminally-ill adolescents not be able to exercise their choice to kill themselves?

And why should I be able to exercise my settled choice to kill myself only if I have less than 6 months left to live, but not 9, 12 or 18 months. Why should the law restrict my personal autonomy in this arbitrary manner?

A settled and 'uncoerced' will to kill oneself

The rhetoric of choice and self-determination sounds compelling from the philosopher's chair or the politician's rousing speech. But in the complexities of human relationships and the play of tragic life circumstances, it is not so simple. Our choices, wishes and desires are all influenced by our societal context and by the web of relationships in which we find ourselves. Is it possible that my choice to end my life is being subtly influenced by the wishes of others?

A previous Commission into assisted suicide concluded that "…it is essential that any future system should contain safeguards designed to ensure, as much as possible, that any decision to seek an assisted suicide is a genuinely voluntary and autonomous choice, not influenced by another person's wishes, or by constrained social circumstances, such as lack of access to adequate end of life care and support."[17]

But although this is clearly well-meaning, it is also frankly absurd. How can we ever be confident that a person's choice to kill themself is not influenced by the wishes of others or by limitations in the social or medical support available? For example, in published reports from the US State of Oregon between 40 and 55% of those requesting medically-assisted suicide gave "Burden on family, friends/caregivers" as a reason.[18]

It is common to find elderly people who are concerned that they are becoming an unwanted burden on their relatives and carers. Desiring to act responsibly and altruistically, they may come to perceive that it would be better for everybody if their life ended. And can we or others always detect the covert influences and emotional factors which lie behind our choices? In the words of Oxford Professor Nigel Biggar, the notion that we are all rational choosers is a flattering lie told us by people who want to sell us something. It is an uncomfortable truth that much of the time we are influenced and motivated by social and psychological forces that we barely understand. Baroness Onora O'Neill has warned that, "incorporating a few 'safeguards' into legislation cannot address the real difficulty of protecting patients against the consequences of choices which are not well-grounded."[19]

So, the burden falls on the attending doctor to ensure that there is no emotional pressure or coercion. But this seems to place unrealistic expectations on a busy professional who may only have a relatively superficial knowledge of the patient's circumstances. It doesn't take a genius to see how the system may fail to spot subtle forms of coercion, manipulation and emotional blackmail. The Bill proposes that a Code of Practice be set up to provide recommendations on best practice for doctors and administrators, but previous experience in the NHS shows that such regulations, although well-meaning, do not prevent egregious failures in practice.

Another common reason given for assisted suicide in Oregon is 'fear of inability to care for self'. There have been well-documented cases in other countries in which worries about the lack of provision of high-quality

---

[17] Falconer Commission on Assisted Dying, https://demos.co.uk/research/the-commission-on-assisted-dying/

[18] Oregon, Death with Dignity Act, 2023 Data Summary

[19] Onora O'Neill "Autonomy and Assisted Suicide" in Julian Hughes and Illora Finlay, The Reality of Assisted Dying, Open University Press, McGraw Hill, 2024

palliative care have been a motivating factor for terminally ill patients to seek assisted suicide. If the Bill becomes law in England it seems likely that some vulnerable people will seek to end their lives because of glaring deficiencies in the social and medical support that is available. But is this something that we as a society should be facilitating by providing lethal drugs?

Although the proposed legislation states that no doctor is under any duty to raise the issues of assisted suicide (clause 4), in the highly regulated and litigious nature of medical care in the UK, once the Bill was enacted, it is likely that the process will become incorporated into standard medical care pathways. In due course it seems inevitable that assisted suicide would be added to the list of 'treatment options' which must be discussed with all patients across England and Wales whenever a terminal illness is diagnosed and made available universally, especially as the Health Secretary has the power to ensure that provision of assisted suicide becomes part of the health service in England and in Wales (clause 32) .

It is inevitable that legal cases will be undertaken against doctors who failed to inform patients that their life expectancy was less than 6 months and hence that they had the option of ending their own lives. To fail to inform patients about the option of suicide, even if the doctor thought it was inappropriate, would be deemed unacceptable and paternalistic.

But once the doctor raises the option of assisted suicide, how many vulnerable people might come to perceive the option to end their lives as a responsible course of action? In the current legal framework, as a terminally ill patient I do not need to justify my desire to continue living, however limited my life may become. But once ending my life becomes a 'treatment option', then I need to provide some reasonable justification for my desire to continue to live, particularly if I am worrying that I might be 'a burden' on my loved ones or NHS resources.

Matthew Parris, writing in The Times, agreed that legalisation of assisted suicide would lead to growing social and cultural pressure on the terminally ill "...to hasten their own deaths so as "not to be a burden" on others or themselves. I believe this will indeed come to pass. And I would welcome it..." As Parris put it, "Your time is up' will never be an order, but — yes, the objectors are right — may one day be the kind of unspoken hint that everybody understands. And that's a good thing."[20]

Mental illness and depression

It seems very likely that the great majority of terminally ill people who choose to kill themselves have at least some elements of what most of us would recognise as depression or persistently low mood. Clinical depression is common in terminal illness and suicidal thoughts are a cardinal symptom of depression. So is it possible for a terminally ill person with depression to make a rational choice to end their own life? Is the desire to end their own life based on a rational appraisal of their situation or is their perception being distorted because of mental illness? One psychologist who had studied people seeking medically assisted suicide in Oregon argued that the distinction was not clear, stating "…of the people who pursue this option, a sizable portion are rationally appraising their situation. And a sizable proportion are appraising it through a lens of depression."[21]

Some in favour of the legislation argue that depression shouldn't necessarily make a person ineligible for physician-assisted suicide. In the normal course of life we don't say that people lose autonomy to make decisions even if they become moderately depressed. Perhaps a degree of depression is a rational response to approaching death.

In summary, the apparently simple principle that people should be legally allowed to achieve their desire to end their lives turns out to be much more murky and complex than might at first seem. In the next chapter we look at some more real-world problems which might result if the Bill became law.

---

[20] https://www.thetimes.co.uk/article/we-cant-afford-a-taboo-on-assisted-dying

[21] Kirsten Weir, Assisted dying: The motivations, benefits and pitfalls of hastening death, https://www.apa.org/monitor/2017/12/ce-corner

CHAPTER 5:

Real world problems

Key Points: *There are practical concerns about the implementation of this Bill from difficulties of determining prognosis, use of drugs not licensed or tested for this purpose, potential complications of ingesting lethal substances, abuse by relatives and the potential for incremental change to make the Bill's application much wider.*

This chapter looks at the realities of how assisted suicide legislation might operate in practice and the real-world problems and issues that could arise.

i) 'Reasonably expected to die within 6 months'

The Bill assumes that taking such a momentous decision as to allow a person to kill themselves can be based on two doctors' prediction that their patient has less than 6 months to live. The myth that doctors are experts in predicting life expectancy is still surprisingly current amongst the public. But there is strong scientific evidence to show just how unreliable medical prognosis is, especially when carried out by doctors who are not specialists in terminal care.[22]

As an experienced NHS consultant, I am all too aware of many examples when I and my colleagues were hopelessly wrong in predicting how many months or years a person had to live. It is not uncommon for a person who is thought to have a 'terminal illness' to live on for years. This may be due to errors in diagnosis, sudden unexpected spontaneous remission, or the development of new treatments and medications. One high profile example of inaccurate prognosis was the Lockerbie bomber Abdelbaset al-Megrahi who was freed from a Scottish prison in August 2009 on the grounds that he was about to die. Detailed medical reports by eminent UK specialists indicated that he had an estimated three months to live with prostate cancer. In reality he survived until May 2012, 2 years and 9 months later.[23]

But prescribing lethal medication means that the prediction of death is of course a self-fulfilling prophecy.. The other problem with the life expectancy criteria is the arbitrary selection of 'within 6 months'. It is wearyingly predictable that if the Bill was passed into law there would be an immediate set of legal challenges to the 6-month criterion. Tragic cases will be presented to the public of people with severe neurological illnesses, such as motor neurone disease, who are desperate to kill themselves but who don't meet the 6-month limit. Don't these tragic people demand our compassion too?

In Canada, following the passing of the Medical Assistance in Dying (MAiD) Act to allow assisted suicide and euthanasia, there have been a continuing series of successful legal challenges over time limits and other restrictions. There seems little doubt that similar legal challenges will commence as soon as any legislation is passed in any part of the UK.

ii) Wrong diagnosis

If only mistakes didn't happen. But I know from painful clinical experience that they do, and they can have devastating consequences. I have seen the reality at first hand through my work as a medicolegal expert witness. Medical disasters are an unfortunate fact of life and serious mistakes in diagnosis are not uncommon, even in specialist centres. The last few years have seen a number of public scares as major errors have been

---

[22] Christakis NA and Lamont EB, Extent and determinants of error in doctors' prognoses in terminally ill patients: prospective cohort study BMJ. 2000 Feb 19; 320(7233): 469–473

[23] http://www.bbc.co.uk/news/uk-scotland-12174643

revealed in pathology laboratories responsible for the diagnosis of cancer. How likely is it that assisted suicide might be carried out in the mistaken belief that the patient was terminally ill, when in fact the disease was self-limiting? Sadly, the legislation would open up yet more possibilities for serious and catastrophic medical mishaps and the long-lasting psychological and professional trauma which results.

iii) Risks from the prescription and supply of lethal substances

The legally approved procedure would require that doctors prescribe and supply to their patients highly lethal drugs for their use only. But the possibilities of errors, accidents and abuse are obvious. The substances have never been properly tested or licensed for killing patients. For obvious reasons, there have been no controlled clinical trials. Possible mishaps, side-effects and contraindications are effectively unknown. Doesn't it seem strange that NHS doctors could be instructed to employ life-terminating substances that have never been properly assessed or licensed!

The Bill proposes that the coordinating doctor (or another delegated doctor) responsible for prescribing the lethal substances, delivers them to the patient personally and waits until the patient had either taken the substances or declined to take the substances (clause 18). Although this proposal seems well-meaning, the presence of the doctor or healthcare professional could clearly provide subtle emotional pressure on the patient to take the lethal medication. It's interesting that in Switzerland, guidelines indicate that the prescribing doctor should not be present when the patient takes the lethal mixture, to avoid any possibility of emotional manipulation.

iv) ensuring a clean death

(This section contains some rather grisly medical details and those of a sensitive disposition may wish to skip to the next section.)

When the euthanasia doctors started killing people some years ago in the Netherlands, they didn't know how to do it. It wasn't the sort of thing you got taught at medical school! There were a number of macabre and failed experiments, but over the years a highly efficient method of ensuring rapid death has evolved, using massive overdoses of old-fashioned sedative drugs called barbiturates. When injected into a vein, and combined with a drug to stop all breathing activity, unconsciousness and death occurs within seconds. This is the method still used in thousands of cases every year in the Netherlands and Canada.

But the Terminally Ill Adults (End of Life) Bill implies that in England and Wales, in the large majority of cases doctors will prescribe lethal medication which will be taken orally by the person seeking to kill themselves. In a published research study of the Netherlands' experience of assisted suicide using oral medication, complications occurred in 7% of cases, and problems with completion (a longer-than-expected time to death, failure to induce coma, or induction of coma followed by awakening of the patient) occurred in 16% of cases. The physician decided to administer a lethal medication (intravenously) in 18% of the cases of assisted suicide because of 'problems with the procedure'.[24] In Oregon, some people have continued living for days after the 'lethal' medication has been given.[25]

Following oral administration of large doses of barbiturates there are also reports of extreme gasping and muscle spasms. While losing consciousness, vomiting and aspiration may occur. Panic, feelings of terror and assaultive behaviour may take place due to drug-induced confusion. The Royal Dutch Medical Association recommends that a doctor be present when assisted suicide is performed, precisely so that a lethal intravenous injection can be given if necessary. Because of problems following oral barbiturates, doctors in

---

[24] Groenewoud JH et al, Clinical problems with the performance of Euthanasia and Physician–Assisted Suicide in the Netherlands, New England Journal of Medicine, Volume 342, Number 8, Feb 2000, pages 551-556

[25] Oregon, Death with Dignity Act, 2023 Data Summary, https://www.oregon.gov/oha/PH/PROVIDERPARTNERRESOURCES/EVALUATIONRESEARCH/DEATHWITHDIGNITYACT/Documents/year26.pdf

the USA are now increasingly using a toxic mixture of heart drugs, sedatives and painkillers.[26] Again, no formal testing or licensing of the strange concoction of pharmaceutical agents has been undertaken.[27]

A Dutch doctor with practical experience of both voluntary euthanasia and assisted suicide said, "Thinking that physician-assisted suicide is the entire answer to the question of ending of life of a suffering patient… is a fantasy. There will always be patients who cannot drink, or are semiconscious, or prefer that a physician perform this act. Experience has taught us that there are many cases of assisted suicide in which the suicide fails. Physicians need to be aware of the necessity to intervene before patients awaken".[28]

While the Bill requires the doctors to discuss what a patient wants to do if there are complications when taking the lethal substances, the options open to the patient are few (clause 9). Doctors would not be allowed to intervene by administering lethal drugs even if severe oxygen deprivation and brain damage resulted from a botched suicide attempt (clause 18). How long before direct medical intervention to end life is seen as an acceptable response when assisted suicide goes wrong?

v) Abuse by relatives

Proponents of assisted suicide dismiss the possibility that relatives might pressurise elderly and infirm people for their own gain. It sometimes appears as though campaigners live in an alternative reality in which individuals make their own autonomous decisions about ending their lives calmly and rationally, and relatives are respectful, compassionate and benign. But in the real world inhabited by clinicians, social workers and law enforcement agencies, this is sadly not always the case and various forms of coercion by relatives is not unusual. It is inevitable that the legislation will open up new possibilities of serious and criminal abuse by family members who see a legally approved opportunity to relieve themselves of a psychological burden, and prevent the dissipation of life savings on expensive nursing care.

A palliative care consultant told me of the relatives of a dying person in her care, who repeatedly expressed concerns that their mother's pain was not controlled. They continued to ask that pain relief and sedation should be increased, although the lady in question appeared settled and peaceful. Subsequently, it became apparent that there was an insurance policy in place and that a substantial amount of money would be paid to the relatives if their mother died before a certain date. Once the date came and went and the patient was still alive, the relatives seemed to lose interest in their mother's pain control.

Of course this is not to imply that most relatives harbour malevolent thoughts towards the terminally ill. But their own emotional distress can be a major source of pressure on other people. "I can't bear to watch her in this state. Why can't you suggest to her that she doesn't need to carry on like this?"

The stories of the relatives of some of those who have taken the journey to the Dignitas clinic in Switzerland illustrate the emotional turmoil that close relatives can find themselves in when a loved-one announces that they wish to kill themselves. Many find themselves conflicted and even subject to a strange kind of emotional blackmail. As one son put it, "When your mother suddenly tells you that she has a terminal illness and is planning to take her own life it is extraordinarily hard…Everybody had always told her not to go ahead with it because there were so many reasons to stay. It was only when she went ahead with the failed attempt that we thought there is no point in messing around; let's do it properly because it's just too cruel to do it any other way."[29]

---

[26] Oregon, Death with Dignity Act, 2023 Data Summary, https://www.oregon.gov/oha/PH/PROVIDERPARTNERRESOURCES/EVALUATIONRESEARCH/DEATHWITHDIGNITYACT/Documents/year26.pdf

[27] Ana Worthington, Ilora Finlay, Claud Regnard, Efficacy and safety of drugs used for 'assisted dying', British Medical Bulletin, Volume 142, Issue 1, March 2022, Pages 15–22, https://doi.org/10.1093/bmb/ldac009

[28] Thomasma DC ed, Asking to Die: Inside the Dutch Debate about Euthanasia, Klewer Academic 2000

[29] http://news.bbc.co.uk/1/hi/health/4625538.stm

vi) Gradual and incremental extension of the grounds for assisted suicide.

As we have seen previously, the proposed grounds for assisted suicide seem unavoidably arbitrary and it is hard to justify them on logical or rational grounds. In a later chapter, we will look at the evidence from Canada which shows how end of life legislation has been open to progressive and repeated extension from the actions of highly motivated campaigners. Even following enactment of the assisted suicide legislation in England and Wales there would still be a steady stream of suffering and tragic individuals who made the journey to Dignitas in Switzerland because they do not meet the definition of terminal illness in the Bill and who demand the right to have an assisted suicide in the UK. So once the proposed law is on the statute book it is surely inevitable that media campaigns and legal challenges will continue, and I find it hard to believe that the grounds for assisted suicide will not be further liberalised in time.

CHAPTER 6:

Medicine and the role of doctors

Key Points: *There is a central role for doctors in this Bill which brings significant psychological and emotional pressure for them and changes their role in our society from healers to active participants in ending their patient's life.*

The Bill makes it plain that medical professionals play a central role in the legally approved mechanism for ending a suitable person's life, placing very onerous and potentially distressing obligations on doctors, from determining terminal illness, assessing legal capacity, determining whether the person has been coerced, planning and delivering the process of life termination, remaining with a person throughout the dying process and then completing the death certification process.

And this raises an obvious question - why? Why is it members of the medical profession who are the ones selected to play a key role in assisting and ensuring the destruction of another person's life?

After all, it is the medical profession who have been trained exclusively to preserve and protect life, including receiving training and developing expertise in suicide prevention. It is the UK medical profession which has always refused to participate in judicial execution, in the use of medical techniques for coercion and torture, in participating in killing as military combatants and so on. Since the time of Hippocrates the medical profession has been the one profession that has dedicated its skills completely to life and to healing, not to killing and suicide. So arguably it should be the last profession to be actively involved in helping people to kill themselves.

If society insists that suicide should be legalised under certain circumstances, why on earth should the duty fall on qualified doctors to organise and conduct the ending of another's life? Would it not be better to train a separate group of individuals who were trained in obtaining a quick and clean death? And if society does insist that it is doctors that play a central role in ending people's lives, what will the consequences be for the future of the profession? Do most people really wish to be looked after by doctors who have become trained and experienced in the grisly mechanics of cleanly ending human lives?

Although it is proposed that no doctor will be forced to participate in ending the life of one of their patients, the Bill states that it is mandatory for them to refer their patients on request to other doctors who are willing to take on this role (Clause 4). It seems likely that it would eventually become mandatory for all doctors to inform their terminally ill patients that assisted suicide was an option and refer them to other doctors for this to be carried out. Will it be possible for doctors who believe strongly that assisting suicide is wrong to continue to work within the NHS, once this becomes common practice in NHS hospitals? How can I continue to work trying to protect the lives of my patients as part of a healthcare team, when other members of the team are discussing the option of suicide with them? The experience of Canada reveals the emotional pressures that some health professionals would be put under to comply with patient requests. And will doctors put all their heart into suicide prevention for the rest of their patients whilst they are also advising some about how to kill themselves?

Psychological and emotional consequences for doctors

Research studies in the Netherlands have shown that there is a significant incidence of emotional distress both in doctors who receive a request for euthanasia and in those who perform the procedure. A review of the research evidence concluded that "the shift away from the fundamental values of medicine to heal and promote human wholeness can have significant effects on many participating physicians. Doctors described being profoundly adversely affected, being shocked by the suddenness of the death, being caught up in the patient's drive for assisted suicide, having a sense of powerlessness, and feeling isolated…."[30]

Why the medical profession?

So why is it that assisted suicide legislation across the world mandates that qualified doctors must play a central role, both in assessing people who are requesting suicide and in prescribing and providing lethal medication? Is it fair that doctors should bear the psychological burdens and consequences of these actions? Why should we not train a cadre of professionally qualified 'euthanasiologists' to undertake these grisly tasks?

But of course, the answer is that as a society we trust doctors to act in our best interests. Opinion polls around the world have consistently placed qualified doctors and nurses as the most trusted professionals.[31] In 2020, when members of the UK public were asked which professions they trusted to tell them the truth, nurses polled 93% and doctors 91%. Judges were rated slightly lower at 84%, lawyers at 61% and politicians at 15%.[32]

So the irony is that members of the public appear to trust doctors when it comes to organising lethal medication, precisely because doctors have developed a centuries-long reputation for being the profession above all that was dedicated to healing and the protection of life!

---

[30] Stevens KR. Emotional and psychological effects of physician-assisted suicide and euthanasia on participating physicians. Issues Law Med. 2006 Spring;21(3):187-200.

[31] https://www.ipsos.com/en-uk/politicians-least-trusted-profession-while-doctors-most-trustworthy

[32] https://www.ipsos.com/ipsos-mori/en-uk/ipsos-mori-veracity-index-2020-trust-in-professions

CHAPTER 7:

Social forces and trends

***Key Points:** Public polling suggests support for this legislation but most palliative care doctors are against a change in the law. This Bill is being debated in the context of public policies to reduce suicides, defend the rights of those with disabilities and care for an aging population with increasing chronic needs who are concerned about being a burden to their families and the NHS/social care.*

There's no doubt that in poll after poll, assisted suicide legislation appears to be astonishingly popular with the public. A YouGov poll published in January 2023 showed that 74% of Britons thought the law should be changed to allow terminally ill adults to "end their life, by life-ending medication with 13% against and 13% 'don't know'".[33] In a previous YouGov poll, 50% of the public were in favour of legislation which included people who were suffering but did not have a terminal illness.[34] It should also be noted that support amongst the public appears to reduce significantly (from 73% to 43%) when arguments against assisted suicide are explained.[35] A poll conducted in June 2024 showed that 56% of those who expressed in principle support for assisted suicide felt there were too many complicating factors to make it a practical and safe option to implement in Britain.[36]

Other studies have shown that the further people are away from the realities of terminal illness, the more they are in favour of legalising various forms of assisted suicide and euthanasia. Alternatively, the closer people are to daily practical experience of caring for dying people, the more likely they are to be opposed to a change in the law. Senior doctors are much more cautious compared with lay-people and repeated surveys have demonstrated that the majority of UK palliative medicine doctors (70-84%) are not in favour of legalising assisted dying and 75-84% of them would be unwilling to participate in the process.[37]

Of course, it's possible to portray this as illustrating the innate conservatism of the medical profession, but this is surely naïve and simplistic. There is something much more significant in the contrast between public opinion and the views of those who work all day with patients who are facing death.

Part of the problem is that death has become very 'medicalised' in the UK. We are much less familiar than we used to be with death and dying and we find it hard to accept that the dying process is a natural and normal part of human existence. Dying has been banished to hospitals and medical institutions and most people have had no personal experience of watching someone die at close quarters. We want to keep death at arm's length. The thought of having to experience one's own death has become frightening and unthinkable. It's not surprising that the option of avoiding all the unpleasantness by 'taking a few tablets' sounds deceptively attractive.

All experienced clinicians are aware of a disconnect between how people talk in theory about death and dying when they are still healthy, and their attitudes and decisions once they are actually confronted with

---

[33] https://d3nkl3psvxxpe9.cloudfront.net/documents/DiD_Inquiry_230114.pdf

[34] https://yougov.co.uk/topics/health/articles-reports/2021/08/04/three-quarters-britons-support-doctor-assisted-sui

[35] https://www.carenotkilling.org.uk/public-opinion/assisted-dying-public-opinion/

[36] https://livinganddyingwell.org.uk/assisted-dying-too-many-complicating-factors-to-be-safely-implemented-says-british-public-in-new-poll/

[37] https://www.bmj.com/content/387/bmj.q2351/rr-1

the reality of death. In the pub, with pint in hand, or around the dinner table, it's common for people to say something like, 'Of course if it was me, I would say, I've had a good life, but now it's time to go. I don't want to linger on. Give me the medicine, doc….'. So, when polled, they are going to be strongly in favour of a law that allows them to do just that.

But the very human reality is that everything changes when that same person is receiving the diagnosis of advanced disseminated cancer from their oncologist. The desperate desire to hang onto life, whatever the cost, is so often overwhelming. Samuel Johnson's aphorism "When a man knows he is to be hanged in a fortnight, it concentrates his mind wonderfully", is relevant to terminal illness too. So, I am deeply sceptical about the attitudes to death, suffering and suicide which are expressed in public opinion polls. Perhaps it really is better that we listen to the voices of those who regularly counsel, support and care for dying people.

Suicide and society

It's easy to overlook the efforts that we take as a society to persuade people not to end their own lives. Every health professional, social worker, policeman and prison officer in the UK receives extensive training on how to detect individuals who are at risk of suicide, how to minimise the risk and what immediate steps should be taken if the risk of someone ending their life is severe. All health professionals understand that the imminent risk of suicide represents a medical emergency, just as much as a cardiac arrest, and that immediate steps must be taken, including forcibly detaining people in a hospital or other place of safety.

The General Medical Council, in guidance for doctors in 2013, stated "Where patients raise the issue of assisting suicide, or ask for information that might encourage or assist them in ending their lives, doctors should be prepared to listen and to discuss the reasons for the patient's request but they must not actively encourage or assist the patient as this would be a contravention of the law".[38]

The Samaritans, whose stated vision is that 'fewer people should die by suicide', receive a call every ten seconds in the UK and had over 20,000 trained listening volunteers responding to calls for help.[39]

None of this extraordinary opposition to suicide has happened by accident. It reflects the profound intuitions we all share that when a person acts to end their own life it is profoundly destructive and damaging to everyone, an act of despair and hopelessness which should be resisted with all the energy that society can muster. And studies have repeatedly demonstrated the deep and lasting psychological trauma that suicide can inflict on relatives, loved-ones and carers.

It has been argued that the legalisation of 'assisted dying' might reduce the overall incidence of suicide. However, in other countries that have introduced laws to allow medically assisted suicide, there is no evidence that the overall rate of suicide has declined. In fact, a historical survey of suicide rates in several US states between 1990 and 2013 showed a statistically significant rise in overall suicide rates, particularly in older people, following the introduction of medically assisted suicide.[40] There is also evidence that news about suicides given high profile by the media may lead to an increased incidence of 'copy-cat' suicides, an effect sometimes known as 'suicide contagion'.[41] [42] [43]

---

[38] https://www.gmc-uk.org/professional-standards/professional-standards-for-doctors/when-a-patient-seeks-advice-or-information-about-assistance-to-die

[39] What we do | Samaritans

[40] Jones DA, & Paton D, How does legalization of physician assisted suicide affect rates of suicide? Southern Medical Journal, 2015, 180(10), 599-604.

[41] Jones DA, Assisted dying and suicide prevention, Journal of Disability & Religion, 2018, 22(3), 298–316.

[42] Paton D & Girma S, Assisted suicide laws increase suicide rates, especially among women, Centre for Economic Policy Research (CEPR), 2022 https://cepr.org/voxeu/columns/assisted-suicide-laws-increase-suicide-rates-especially-among-women

[43] Jones DA, Euthanasia, Assisted Suicide, and Suicide Rates in Europe, Journal of Ethics in Mental Health, Open Vol 11, 2022 https://irp.cdn-website.com/c0d44f22/files/uploaded/JEMH_article_EAS_and_suicide_rates_in_Europe_-_copy-edited_final.pdf

The existing law against assisted suicide has a highly significant role in symbolising our community's profound disapproval of suicide. Changing the law to license doctors to supply lethal drugs sends the message that under certain circumstances we approve and agree with terminally ill patients ending their lives. By legalising suicide, even under very restricted circumstances, are we tampering with some of the deepest human ties which still bind our community together?

Societal and economic context

We cannot isolate individual decisions in which terminally ill people may choose to end their lives from the societal and economic context in which those decisions are embedded. In particular, it's essential to think about the impact of the marked increase in the numbers of elderly and frail people in our midst, and the social, medical and economic pressures which this inevitably creates.

In England and Wales in 2021 there were over 11 million people aged 65 years and over,[44] and 1.6 million people aged more than 85 years in the UK as a whole (2.5% of the population).[45] By 2036, it is expected that number will increase to 3.5% of the population.[46]

The startling increase in the number of older people is happening at time when there is a progressive weakening and breakdown of traditional family structures. There has been a steady increase in the numbers of people who are living alone. In the whole of the UK this rose from 7.5 million to 8.2 million between 2009 and 2019, of which nearly half (49.1%) were aged 65 years and over, and more than one out of every four (29%) were aged 75 years and over.[47]

Health consequences of an ageing population

Improvements in healthcare and medical technology have contributed directly to the increase in lifespan. This is surely a good thing, but it has had unforeseen consequences in increasing the number of elderly people who have chronic health needs. Approximately 20% of people aged 70 years or older, and 50% of people aged 85 and over, report difficulties in such basic activities of daily living as bathing, dressing, toileting, continence, feeding, and transferring from a chair to a bed.[48] As life expectancy increases, so does the likelihood of more years spent in ill health, with women at present having on average 11 years and men 6.7 years of 'poor health'.

Disability rights

Many disabled people, including the campaigning group Not Dead Yet, have been vocal in their opposition to the Bill. They argue that the distinction between disability and terminal illness is a myth because definitions of 'terminal illness' can never be precise. As a result, disabled activists believe that a significant number of people who would be affected by assisted suicide legislation will be disabled people. The legislation would represent just one more way in which society as a whole discriminates against disabled people and devalues their lives.

It is dangerously simplistic and disingenuous to argue that autonomous decisions about ending one's life can be taken without considering the pervasiveness of discrimination, and the failures to comprehend and respect the realities of the lives that disabled people experience every day. As disabled campaigners put

---

[44] Office for National Statistics https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/ageing/articles/profileoftheolderpopulationlivinginenglandandwalesin2021andchangessince2011/2023-04-03#population-ageing

[45] Office for National Statistics https://www.ons.gov.uk/peoplepopulationandcommunity/populationandmigration/populationprojections/bulletins/nationalpopulationprojections/2021basedinterim

[46] Ibid

[47] Office for National Statistics https://www.ons.gov.uk/peoplepopulationandcommunity/populationandmigration/populationestimates/articles/overviewoftheukpopulation/january2021

[48] https://www.ageuk.org.uk/globalassets/age-uk/documents/reports-and-publications/reports-and-briefings/health--wellbeing/age_uk_briefing_state_of_health_and_care_of_older_people_july2019.pdf

it, “In these days of cost cutting in the NHS and social care, assisted suicide could all too easily become an attractive ‘treatment’ remedy.”[49]

No mainstream organisation of, or for, disabled people supports a change in the law on assisted suicide or euthanasia. Yet their voice is scarcely heard in the public debates. As one disabled person put it, “we simply do not have the same resources as multi-million-pound, celebrity-endorsed campaigning organisations… many disabled people fight to get through each day, in spite of their disabilities, but using their capacity to take on high level policy battles at the same time can be exhausting. Faced with a glamorous celebrity-endorsed campaign for a change in the law, the already struggling disabled voice fails to make an impression.”[50]

How do these societal and economic factors influence the debate about assisted suicide?

Nearly all of those who are arguing for a change in the law explicitly distance themselves from any argument based on the benefits for society as whole. But it is remarkably naïve to think that social and economic realities will not influence the choices that elderly people make when offered the option of ending their lives.

The people whose high-profile cases come to media attention are usually strong-willed individualists who see the law against assisting suicide as a nuisance. But they are very much in the minority. Most people when they are seriously ill are less concerned with asserting their will, and more concerned with trying to cope with the practical challenges they are facing. It is true that there are a small number of individuals with terminal illnesses who wish to be helped to end their lives. But there are hundreds of thousands of elderly people struggling with chronic ill health, disability and illness who wish to live. How will these people perceive their lives when the offer of a legally assisted suicide is given to them by a doctor they trust? It is common to find elderly people who are concerned that they are becoming an unwanted psychological and financial burden on their relatives and carers and they may come to believe that it would be better for everybody if the offer of ending their lives was accepted. The current law exists to protect people who are at risk of subtle and coercive pressure from others.

In the next chapter we look at what we can learn from the experience of Canada, where medically assisted suicide and euthanasia has recently become integrated into the state-supported health services.

---

[49] http://notdeadyetuk.org/about/

[50] Tanni Grey-Thompson and Flora Klintworth, “Disability – a duty to die?” in in Julian Hughes and Illora Finlay, The Reality of Assisted Dying, Open University Press, McGraw Hill, 2024

CHAPTER 8:

Lessons from Oregon and Canada

Key Points: *We should learn from the experiences of other jurisdictions. Oregon was the first state in the USA to change their law and is often cited as a beacon for change. However, there is limited transparent data, few people are referred for psychiatric evaluations, and there have been incremental changes in the 'safeguards'. Importantly, a significant number report choosing an assisted suicide because they feel a burden. Other US states have followed the Oregon model but have made changes to their laws to remove 'safeguards' that are now seen as 'barriers to access', including residency requirements, who can prescribe medication and reductions ine the reflection periods. Others are campaigning for widening the criteria beyond terminal illness. Canada's law has been extended through court cases to go beyond terminal illness and will encompass mental illness in 2027. There are numerous reports of individuals choosing to die under the Canadian law because of inadequate social care. There are significant*

Oregon

The US State of Oregon is often cited by UK campaigners as an excellent and reassuring model for assisted suicide legislation. For instance, a 2021 BMJ article claimed "In Oregon, where assisted dying has been legal for nearly 25 years and maintains public support, it is strictly monitored, and there are no reports that the law has been misused."[51] However there are many reasons to think that this is a gross over-simplification – the reality is much more complex.

The Death with Dignity Act (DWDA) came into force in 1998 and has been in operation since then. The Act allows the prescription of lethal medication to Oregon residents who are 18 years or older, acting voluntarily, capable of making and communicating health care decisions and diagnosed with a terminal illness that will lead to death within 6 months. Two doctors must certify that a patient meets the criteria prior to providing the lethal drugs and provide notification to the Oregon Health Authority. An annual report is published providing statistical information.[52]

The official annual reports provide valuable statistical information, but they provide virtually no details on what actually happens when a doctor receives a request for lethal drugs and gives no data on those who have been refused. In 2023, 560 people received prescriptions for lethal drugs and 367 people were known to have died from the drugs. An additional 82 (15%) did not take the lethal drugs and later died of their terminal illness. Ingestion status was unknown for 141 patients (25%) prescribed DWDA medications in 2023.

Only 3 out of the 367 people who died had been referred for psychiatric evaluation. This seems a remarkably low figure given the frequency of mental health issues, such as depression, in those with terminal illness.

The most common reasons given for obtaining the lethal drugs were "losing autonomy" (92%), "less able to engage in activities making life enjoyable" (88%) and "loss of dignity (64%). "Burden on family, friends/caregivers" was cited in 43% of cases and 34% stated "Inadequate pain control or concern about it". Thirty people (8%) stated "financial implications of treatment". One Oregon doctor commented "They are not using assisted suicide because they need it for the usual medical kinds of reasons, they are using it because

---

[51] Richard Hurley et al, BMJ 2021;374:n2128

[52] https://www.oregon.gov/oha/PH/PROVIDERPARTNERRESOURCES/EVALUATIONRESEARCH/DEATHWITHDIGNITYACT/Documents/year26.pdf

they tend to be people who have always controlled the circumstances of their lives and they prefer to control their death in the same way".[53]

In all cases the attending physician ticked boxes on the regulatory forms to certify that the patient had a 'terminal illness', was 'capable' and was 'acting voluntarily' but no further information is provided about the nature of the conversation(s) that occurred, and whether any other health providers, relatives or friends were involved. Given that more than 40% of patients recorded "being a burden on friends and relatives" as a reason for requesting lethal drugs, it is clear that there are many possibilities for inappropriate coercion and manipulation from others.

Oregon is very different from the UK in that registration with a local GP practice is not routine and healthcare is provided on an insurance basis with individuals likely to be paying to see a doctor. It is remarkable that the median duration of the doctor-patient relationship was only 6 weeks prior to the death and in at least one case it was less than 1 week. A total of 167 physicians were involved in providing prescriptions and one physician provided prescriptions to no less than 76 different individuals in 2023. Since many family doctors in Oregon refuse to prescribe lethal drugs, there have been concerns about 'doctor-shopping', patients seeking out doctors who are known to be favourable to assisted suicide, when they decide to end their lives.

It is often claimed that 'there is no evidence of abuse' and the official 2023 report stated that the Oregon Health Authority made no referrals to the Oregon Medical Board for failure to comply with DWDA requirements. However, the Health Authority has stated that 'it does not investigate whether patients met the DWDA criteria, nor how their diagnosis, prognosis and treatment options were determined'. Indeed, the Health Authority website states that 'the law does not include any oversight or regulation that is distinct from what is done for other medical care'. It is clear that the Health Authority only investigates individual cases if a formal complaint is received. Otherwise, provided that the appropriate boxes have been ticked on the regulatory forms, it is assumed that no abuse has occurred. This is very different from the regulatory regimes in other countries, such as the Netherlands, which undertakes detailed reviews of the adequacy of the assessment procedures.

One of the most remarkable features of the Oregon experience is the progressive rise in lethal prescriptions and deaths since the law came into force. If anything, the rate of increase seems to be accelerating over the last few years. There has been a nearly 10-fold increase in the numbers dying between 2000 and 2020. There is certainly no evidence that the number of people who are dying following lethal drugs is stabilising or reaching a plateau.

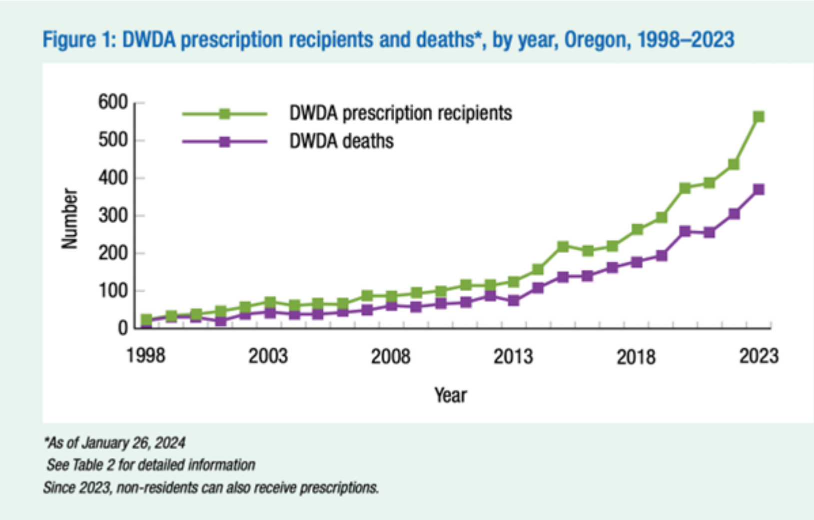
Figure 1: DWDA prescription recipients and deaths*, by year, Oregon, 1998–2023

*As of January 26, 2024
See Table 2 for detailed information
Since 2023, non-residents can also receive prescriptions.

Figure taken from Oregon Health Authority, Oregon Death with Dignity Act, 2023 Data Summary

---

[53] Evidence to the 2004 Select Committee on Assisted Dying Bill http://www.publications.parliament.uk/pa/ld200405/ldselect/ldasdy/86/4120922.htm

Given the awesome responsibility of providing lethal drugs and the self-fulfilling nature of the diagnosis of terminal illness, legal capacity and voluntary choice, the official reporting and regulatory process is surprisingly limited and 'light touch'. There appears to be no attempt by the health authorities to check on the thoroughness or reliability of the assessment process, and there is complete trust that when doctors tick a series of boxes to certify that a patient has a terminal illness, has legal capacity and is acting without any coercion, then this will always be the case. All the case documentation is destroyed after one year. Remarkably, doctors are also instructed to certify the death as 'natural' on death certificates.

If there is little information about the adequacy of the assessment process from the official figures, what about evidence from independent sources? In 2008, a study by Linda Ganzini, Professor of Psychiatry in Oregon, concluded that one in six of a small sample of patients which died by lethal drugs had been suffering from undiagnosed depression.[54] Ganzini has also stated that the majority of Oregon psychiatrists were confident that, in the context of a long-term relationship, they could determine whether a mental disorder such as depression was influencing the decision for physician assisted death, but very few thought that it was possible to assess this in a single visit.

So in conclusion, is it really true that Oregon provides a compelling example of how assisted dying legislation should be enacted? Are the actions of doctors 'strictly monitored' and can we be confident that the system is free of abuse, as has been claimed by campaigners here in the UK? It has repeatedly been said of doctors that 'they bury their mistakes'. Given the lack of rigorous review of deaths under the DWDA, and the destruction of case records after one year, it seems highly likely that this is happening in Oregon too.

Oregon was seen as a forerunner for the law for the other US states that have adopted similar legislation but have made changes to their laws to remove what were originally conceived as 'safeguards' and are now seen as 'barriers to access', including residency requirements, who can prescribe medication, and reductions in the reflection periods. Others are campaigning for widening the criteria beyond terminal illness.

There is no denying that the rugged libertarian culture of Oregon is profoundly different from that of the UK. Canada, of all those countries that have legalised forms of medically assisted death, is the most similar to us in terms of a state-funded and nationalised health service, liberal democratic Anglo-Saxon values and strong law-based regulatory frameworks for health and social care.

If we want to see what the future of legislation might look like, then it might be argued that Canada provides a foretaste.

Canada

A decade ago, Canada was in a very similar position to the UK today. Although there were continuing legal and parliamentary debates there was no real progress towards the activists' dream of legalised euthanasia and the medical profession remained opposed.

But in 2011 there was a fresh legal challenge which was based especially on the case of Kay Carter, an 89-year-old suffering from a degenerative spinal condition, who had travelled to the Dignitas clinic in Switzerland so she could end her own life one year earlier.

In 2012, the Supreme Court of British Columbia agreed with the legal challenge and ruled that the current laws prohibiting assisted suicide were unconstitutional. The case went ultimately to the Canadian Supreme Court. The Canadian Medical Association (CMA), which had previously been opposed to assisting suicide, underwent a sea change. For decades, the CMA had been firmly opposed to doctors having anything to do with assisted suicide or euthanasia. In 2011 a poll had indicated that just 11% of Canadian doctors

---

[54] Ganzini L et al, BMJ, 2008;337:a1682

would take part in euthanasia or assisted suicide if it were legal. But in 2014, the body changed to formal neutrality, arguing its members were too divided on the issue. Then the CMA went further, contributing evidence to the Carter Supreme Court case. In fact, the president of the CMA stated that its members must be front and centre in the drafting of new laws.[55] [56]

In 2015, the judges of the Canadian Supreme Court issued their verdict, in the case which was known as Carter v Canada. The judges ruled that the existing law forbidding medically assisted suicide was unconstitutional and the federal government was told that it had just 12 months (later extended to 18) to develop and pass a law regulating a new right to both euthanasia and assisted suicide. In the summer of 2016, the federal government introduced the Medical Assistance in Dying (MAiD) Bill.[57]

It's remarkable to observe what has happened in the 8 years that have passed since the first patient died under the MAiD law. The original legislation laid out a clear and supposedly rigorous process before someone could be 'assisted to die'. To be eligible you had to be 18 or older, mentally competent, suffering from a serious physical health condition and in an advanced state of decline, and someone whose natural death was 'reasonably foreseeable'.

At the time MAiD became law the regulations were hailed as thorough, thoughtful, rigorous; meeting Canada's needs for a well-regulated assisted suicide and euthanasia system. Most of those advocating for MAiD insisted, much as their British counterparts do today, that all they wanted was a modest system for exceptional cases. But the moment that the legislation was passed, demands for further liberalisation began.

In the first months after legalisation, about 115 people per month took up the new option of an assisted death. But in 2022, there were 1,100 MAiD deaths a month, accounting for over 4% of all deaths, and 6.6% of deaths in Quebec.[58] Within six short years from legalisation, Canada surpassed all other countries for euthanasia and assisted suicide deaths. And the figures seem to increase relentlessly year on year, as they have in other countries that have legalised assisted suicide or euthanasia.

But the most startling changes have been in the eligibility criteria for MAiD. The original legislation restricted access to those who were terminally ill and close to death. Although there was no specified time limit in the legislation, a 'reasonably foreseeable natural death' was interpreted by doctors and lawyers to mean at most a few months left to live.

Shortly after MAiD came in, one government minister mentioned that Kay Carter, whose death at the Dignitas clinic in Switzerland had sparked the original court case, would have been eligible for the new procedure. Seizing upon this remark, Canada's most famous pro-euthanasia doctor, Ellen Wiebe, used actuarial tables to establish Carter would have lived another five years at the time of her death. She then argued that given this was the new cut-off point for MAiD eligibility, the timeline should be expanded ten-fold.[59]

Then, in 2017, an Ontario court ruled that a woman with osteoarthritis, referred to as AB, was eligible too for MAiD. In 2019 two disabled people in Quebec challenged the MAiD regulations which required patients to be terminally ill at all. The court ruled in their favour, telling the government that euthanasia had to be available to everyone who was suffering, even to those at no risk of dying from their conditions. As a result, in March 2021 an amended MAiD bill was passed by the Canadian parliament striking out any requirement to be terminally ill, and allowing patients with chronic disabilities to receive euthanasia.[60] The MAiD

---

[55] https://www.cma.ca/medical-assistance-dying

[56] https://www.consciencelaws.org/background/procedures/assist029-01.aspx

[57] https://www.parl.ca/DocumentViewer/en/42-1/bill/C-14/royal-assent

[58] https://www.canada.ca/en/health-canada/services/publications/health-system-services/annual-report-medical-assistance-dying-2022.html

[59] https://www.theglobeandmail.com/opinion/sandra-martin-physician-assisted-death-debate/article37742446/

[60] https://www.justice.gc.ca/eng/cj-jp/ad-am/bk-di.html

legislation has also been amended to allow a patient to enter into a written arrangement to receive MAID even if they lose capacity before it is scheduled to be administered.[61]

The original MAiD law stated that only adults aged 18 or over could be approved for euthanasia. But a report by the Canadian Paediatric Society in 2018, just two years after legalisation, found parents of sick or terminally ill children were already regularly asking doctors for MAiD. In one survey, 11% of paediatricians said they had had exploratory discussions about MAiD with parents, despite such a prospect being entirely illegal. Over half of the children whose parents had requested they receive mercy killing were under the age of one.[62] A Canadian Parliamentary report recommended further work to decide if mature minors could become eligible for MAiD.[63]

At first, palliative care doctors were strongly opposed to MAiD, but over time, as palliative care specialists found more of their patients demanding euthanasia, they came under increasing criticism from activists. It is clear that a number of palliative care services have now accepted MAiD and in 2019, the annual figures showed that more than one in five of all deaths by lethal injection occurred in hospices.[64]

At conferences for pro-MAiD doctors, activists have spoken of their intent to wear down palliative care physicians and hospices over time, gradually eroding their resistance until no institution feels able to claim their legal right to conscientiously object. Others insist the government should remove funding from healthcare institutions which refuse to carry out MAiD.

A similar process is underway with faith-based hospitals and clinics, which are a significant feature of Canada's state-funded healthcare system. Currently, institutions which have moral objections to MAiD (mostly Christian-founded hospitals) can opt out entirely from fulfilling patient requests. But cases where severely ill patients have needed to be transferred from their faith-based hospital in order to fulfil their desire to be killed have received prominent attention in the media.

In one controversial case, a hospital in Nova Scotia, which was founded by nuns, was handed over to the provincial health authority in the 1990s on the proviso that their Christian convictions would be upheld. But once MAiD was legalised, critics argued this exemption was unfair as it forced locals to travel further afield to find a doctor willing to give them a lethal injection. 'Dying With Dignity', Canada's leading pro-euthanasia lobby group, threatened to sue the hospital, and prominent bioethicists strongly criticised religious exemptions. In the face of this campaign, the hospital management caved in and now allows both assessments and the administration of MAiD on its site.[65]

There are continuing discussions about whether MAiD should be available to "mature minors" and whether individuals can decide in advance whether they want to die under the law,[66] but very little discussion about how to improve the robustness of data collection and identifying any abuses.[67]

There are worrying stories from Canada about the reasons individuals are choosing to end their lives.[68] A 2023 journal article stated, "there is a growing accumulation of narrative accounts detailing people getting MAiD due to suffering associated with a lack of access to medical, disability, and social support."[69]

---

[61] https://www.cmpa-acpm.ca/en/advice-publications/browse-articles/2021/the-continuing-evolution-of-medical-assistance-in-dying

[62] Dawn Davies, Paediatrics & Child Health, 2018, 125–130. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5905504/pdf/pxx181.pdf

[63] Medical Assistance in Dying in Canada: Choice for Canadians (parl.ca), February 2023

[64] https://www.canada.ca/en/health-canada/services/medical-assistance-dying-annual-report-2019.html

[65] https://globalnews.ca/news/5917973/nova-scotia-health-authority-st-marthas-regional-hospital-assisted-dying/

[66] Medical Assistance in Dying in Canada: Choice for Canadians (parl.ca), February 2023
Statement from Minister of Health and the Minister of Justice and the Attorney General of Canada on advance requests for medical assistance in dying - Canada.ca 28 October 2024

[67] Coelho, R., Maher, J., Gaind, K., & Lemmens, T. (2023). The realities of Medical Assistance in Dying in Canada. Palliative & Supportive Care, 1-8. doi:10.1017/S1478951523001025

[68] https://www.spectator.co.uk/article/why-is-canada-euthanising-the-poor- 30 April 2022

[69] Coelho, R., Maher, J., Gaind, K., & Lemmens, T. (2023). The realities of Medical Assistance in Dying in Canada. Palliative & Supportive Care, 871-8. doi:10.1017/S1478951523001025

So, what can we learn from Canada? In just eight years, eligibility for medically assisted death has been widened enormously and it is still being pushed further by activists. Canadian doctors have undergone a volte face, changing from opposition to enthusiastic support for extending the law to people with dementia and minors. The requirement to be terminally ill has been abolished, and the exclusion of mental health conditions will lapse in two years' time. The numbers receiving lethal injections are increasing year on year. Conscience protections for faith-based hospitals have counted for little in the face of strong public pressure to allow MAiD, while the almost centuries-old tradition of palliative care has partly dropped its opposition to euthanasia.

CHAPTER 9:

A better way: expert palliative care

***Key Points:** The UK has been a leader in palliative care but it is significantly underfunded with only a third of hospice funding provided by the Government so there are many individuals who are ending their lives in uncontrollable pain and without adequate care. Palliative care represents a tiny fraction of total NHS spending. The issue is about our priorities in allocating healthcare resources.*

If the introduction of legally approved suicide is so fraught with problems and unforeseeable dangers, then what on earth is our response to those thousands of people who seem to be dying badly in our advanced societies? Yes, hard cases make bad laws, but surely as a society there is something we can do to improve the experience of dying people across the country.

Many of the answers can traced back to a remarkable group of pioneers in the UK in the 1950s and 1960s, especially Dr Cicely Saunders. She was an extraordinary person who pioneered a new way of caring for dying people that went round the world, and her remarkable initiative still reverberates today. Initially she trained as a nurse and then as a medical social worker in London in the 1940s. At that time traditional medical practice placed little emphasis on the care of dying people, who were often grossly neglected and abandoned in their final days and weeks.

Cicely was deeply moved by her experience of caring for a dying patient over the last two months of his life and this experience became the touchstone for her life. She decided to devote her life to the care of dying people and at the age of 33 she enrolled as a medical student at St Thomas' Hospital in London and trained as a doctor. Her strong Christian faith combined with a deeply compassionate nature, produced an innovative and creative approach to caring, and a steely determination to do the best for her patients.[70]

Dealing with "total pain"

One of her most profound insights was the concept of 'total pain'. An elderly person was dying of cancer. There was gnawing and continuous physical pain because the cancer cells had invaded the bone. The physical pain was incessant, destructive, and dehumanising. But there was also mental or psychological pain, anxiety about what each day might bring. Often the fear of pain was as bad as the pain itself. Maybe there was despair and a sense of hopelessness at the recognition that life was coming to an end. Then there was relational pain, concerns about the effect of the cancer on a spouse or child. Perhaps there had been no contact with the oldest son for years, and now death was coming with no chance of reconciliation.

And finally, there was spiritual or existential pain, maybe from feelings of unacknowledged guilt from past events, or a sense of the meaninglessness of existence. Cicely realised that each form of pain had to be addressed in order to maximise the well-being of the patient over the critical hours and days as death approached. She discovered that if anxiety, loneliness and spiritual pain were recognised and tackled, then very often the physical pain was much easier to control and alleviate.

It is a common observation of palliative care doctors that when physical pain does not seem to respond, despite the administration of powerful medical treatments, it is highly likely that psychological, relational and spiritual factors are involved, and these must be addressed.

---

[70] Shirley du Boulay, Cicely Saunders, the founder of the modern hospice movement, SPCK 2007

The palliative care pioneers employed the latest pharmacological research evidence on pain-killing medication, together with meticulous observation and documentation from thousands of patients. They showed that it was possible for virtually all physical pain to be abolished or at least substantially reduced, without causing extreme sedation and drowsiness. Their aim was that patients should be alert and able to respond to family, relatives and carers in the vital last days and hours of life.

Not just physical pain, but all unpleasant symptoms - nausea, itching, cough, dry mouth and so on - were to be addressed in painstaking detail with skilled nursing care. Psychological pain was tackled with human contact, friendship, music, humour, and encouragement of hobbies and interests, as well as professional counselling and support when necessary. Relational pain was approached by supporting and encouraging family members to be present, and encouraging openness and honest communication.

She commented: "Though we cannot heal there is a great deal that can be done to relieve the suffering of every dying person." Another pioneer of the movement, Robert Twycross, wrote: "Palliative care developed as a reaction to the attitude, 'There's nothing that can be done for you'. This is never true. There's always something that can be done."

Cicely pioneered an approach which puts the dying individual at the centre of care. Concern for the individual wishes and needs of each individual is at its heart. Pillows are arranged and rearranged, screens are moved an inch or two until a comfortable position is found for the patient who cannot move their head. There is endless meticulous attention to mouth care, bathing sore eyes, putting cream on itchy skin, and placing cushions between aching knees.

Being there

But above all Cicely and her colleagues discovered that it is not primarily about doing things to patients – it is about "being there" for each individual. Through a number of intense and personal experiences of caring she learnt that "it was possible to live a lifetime in a few weeks; that time is a matter of depth, not length; that in the right atmosphere and with pain controlled so that the patient is free to be herself, the last days can be the richest, they can be a time of reconciliation that makes the dying peaceful and the mourning bearable."[71]

One of the best known of her sayings is "You matter because you are you, and you matter to the end of your life. We will do all we can not only to help you die peacefully, but also to live until you die." 'To live until you die' became one of the slogans of a new kind of caring and the foundation of the medical specialty of palliative care.

Cicely Saunders and St Christopher's Hospice in South London became the hub of a movement that has spread out across the world. The philosophy and principles of palliative care were established and taught, research into pain relief and symptom control took off and training programmes were established. Many other hospices were established but increasingly the principles and practices of palliative care were extended into the community, to help people dying at home, and into general hospital practice. What Cicely had founded was a concept, an approach to the individualised care of the whole person, and so much more than an institution.

Dying Well

As a front-line doctor who worked in the NHS for more than 30 years, I have had the privilege of caring for many dying people over the years - adults, children and babies - and I have seen first-hand how effective the kind of palliative care that Cicely Saunders pioneered can be. The death bed does not have to be a place of doom and gloom. In fact, for some people there is the surprising opportunity of intense and wonderful life in those last days and weeks – 'to live before you die'. Many people have found that dying well with excellent pain and symptom control can be an opportunity for focussing on the things that matter. Dying well can be

---

[71] Shirley du Boulay, Cicely Saunders, the founder of the modern hospice movement, SPCK 2007

an opportunity for re-ordering priorities, for expressing what is really important in life. When faced with our own imminent mortality we have an opening to learn what really matters to us. We learn about ourselves and what is really in our hearts. For good or ill, dying can strip us of pretence and illusion, and reveals our deepest concerns.

A close friend of mine, a young man in his 30s, who found that he only had a few months to live, decided that he would write a personal letter to everyone who had been significant in his life, sharing his heart and experiences, and his personal faith. Those last months turned into a rich and remarkable experience that touched hundreds of other lives. For some the knowledge that life is drawing to an end gives an opportunity for fulfilling life-long dreams. Many people have found that it is only when they are dying that deep dreams and longings can come to the fore: they can be verbalised, recognised and acknowledged.

Dying well can be an opportunity for healing from the inside. For many who are facing death, it is relational pain, the agony of broken and twisted relationships, that is often the deepest suffering. But here is an opportunity for restoration and reconciliation, if only it can be grasped. In those last days and weeks, I have seen how broken relationships and the emotional trauma they bring can be healed in a remarkable and life-transforming manner. Dying well is an opportunity for saying sorry and thank you to those who matter to us. An opportunity for spiritual healing for those traumatised by guilt or perhaps a sense of meaninglessness. It is an opportunity for encouraging those who remain.

Cicely Saunders and the euthanasia debate in the UK

Perhaps it is not surprising that Cicely was strongly opposed to the legalisation of euthanasia and assisted suicide. In 1969, when an early Bill to legalise euthanasia was being debated in the House of Lords she wrote to The Times newspaper, "We, as doctors, are concerned to emphasise that there are few forms of physical distress which cannot be dealt with by good medical and nursing care, that the emotional and spiritual distress of incurable disease requires human understanding and compassion and a readiness to listen and help, rather than a lethal drug."

There is no doubt that the powerful and attractive model of palliative care, which was increasingly spreading across the UK and then across the world, played a vital role in counteracting the legalisation of euthanasia in the UK from the 1960s onwards. Some years ago, I happened to be sitting next to an eminent medical member of the House of Lords who had been at the heart of debates about euthanasia for decades. I asked him in private why he thought that euthanasia had developed in the Netherlands from the 1960s but had not been legalised in the UK, despite numerous attempts. "Oh that's very simple. I can sum up the whole thing in two words: 'Cicely Saunders'."

And yet, and yet. Despite the vital advances in care of the dying which Cicely and her colleagues initiated, and the undeniable fact that the UK still leads the world in palliative care expertise, it seems that this highly effective form of caring is only available for a small minority of people who die in the UK, let alone around the rest of the world. Only about 10% of all deaths in the UK occur in specialist hospices.

There have been several initiatives to take the very best care practices and techniques and make them widely available in NHS general hospitals and in the care of people dying at home. But this has turned out to be much more challenging than had been imagined. High quality palliative care is not technologically sophisticated, but it does not come easily or cheaply. It requires a skilled, experienced and motivated multidisciplinary team available around the clock. It seems scandalous that despite the wealth of expertise that has been built up over the years, so many people in the UK still die without proper care.

Can we afford to provide expert palliative care for everyone who needs it?

In 2015, Deloitte estimated that £4.5 billion was spent on end-of-life care annually, including voluntary donations.[72] Of this estimate, a third (£1.5 billion) related to local authority spending on social care, and a broadly similar amount (£1.3 billion) related to acute hospital care, for people in the last year of life. This last figure is a large sum but it represented just over 1% of the NHS total budget that year. As a country we put vastly more resources into research into finding new treatments for cancer and other means of extending life than we do into providing good palliative care for everyone who needs it. So there is no doubt that we, and all those in developed countries, can afford this kind of care. The issue is about our priorities for allocating healthcare resources.

While only a small proportion of deaths occur in a hospice bed (23,825 deaths, representing 4.5% of deaths, in England in 2021), it is estimated that more than 300,000 people received care from hospices across the whole of the UK in 2020/21. This is a significant number against a backdrop of more than 650,000 deaths in the UK in 2021.[73]

According to a recent report from the House of Lords Library, Hospice UK estimated that hospices receive only one third of their income from the government and that in September 2024 that the sector is heading for a deficit in the region of £60 million for the current financial year.[74] The organisation said that the 2023/24 financial year "was by a distance the worst financial year we have ever seen for the hospice sector". It was "therefore very concerning that the first quarter results in 2024/25 have been significantly worse than for the same period last year".

The All-Party Parliamentary Group (APPG) on Hospice and End of Life Care published a report on government funding for hospices in January 2024.[75] The APPG found the hospice sector's reliance on fundraising for most of its income "carries huge risk" as "the volatility of this income makes it hard to plan for the future and puts services perpetually at risk". It also found this funding model "deepens socio-economic inequalities" as communities in the most economically deprived areas were less able to donate to their local hospice than those in more affluent areas, and this could affect local service provision.

The APPG said NHS commissioning of hospice services is "currently not fit for purpose", despite the introduction of a legal requirement to commission palliative and end-of-life care. It pointed to issues such as local contracts not covering the costs of core clinical services and not keeping pace with inflation, and levels of funding for hospices varying significantly across the country and even between neighbouring hospices. The APPG described a "postcode lottery" in the palliative and end-of-life care that populations can access.

Yet there has been much more public outcry about the NHS not paying for extremely expensive and relatively ineffective treatments for cancer, than about inadequate care for the dying.

Surely it is right to fix the funding crisis and ensure that every terminally ill patient in the UK receives high quality care at the end of life, before we contemplate legalising medically assisted suicide.

---

[72] https://committees.parliament.uk/writtenevidence/56726/html/

[73] https://www.nuffieldtrust.org.uk/sites/default/files/2022-06/hospice-services-web-1-.pdf

[74] https://lordslibrary.parliament.uk/hospices-state-funding/#heading-3, October 2024

[75] All-Party Parliamentary Group on Hospice and End of Life Care, 'Government funding for hospices', January 2024.

Further Reading

The Reality of Assisted Dying – understanding the issues, eds Julian Hughes and Ilora Finlay, Open University Press.

Death by Appointment – A rational guide to the Assisted Dying debate, Ilora Finlay and Robert Preston, Cambridge Scholars Publishing

Euthanasia, Ethics and Public Policy: An Argument against Legalisation (Cambridge Bioethics and Law) 2nd Edition, John Keown, CUP

Right to Die? – euthanasia, assisted suicide and palliative care, John Wyatt, IVP

Aiming to Kill – the ethics of euthanasia and assisted suicide, Nigel Biggar, DLT

Cicely Saunders, the founder of the modern hospice movement, Shirley du Boulay, SPCK