

Written evidence submitted by Living and Dying Well (ADY0488)

About Living and Dying Well

Living and Dying Well is an independent think tank which examines issues at the end-of-life, including assisted suicide and euthanasia. As experts in the law, medicine, ethics and related disciplines, we view public safety to be of paramount importance. We respect the motivations of those taking a different view, but have seen no evidence that 'assisted dying' legislation would ameliorate deficits in care.

Issues particularly relevant to England and Wales

There is an acute workforce shortage across Health and Social Care and amongst those who work daily with patients with severe life-limiting and terminal illnesses. The majority of these doctors neither support a legal change nor would they personally be involved.¹

What is assisted dying?

The term 'assisted dying' is used flexibly to cover assisted suicide - providing the means (lethal drugs) for a person to end their life - and euthanasia, where lethal drugs are administered by injection

Legally, suicide is the taking of one's own life, with or without the help of any other. Regardless of the context or intention of 'assisted dying', it is important that the language remains legally accurate.

Where both physician-assisted suicide and euthanasia have been legalised, data from the Netherlands and Canada show that euthanasia rapidly becomes the practiced mode of 'assisted' death.

The criteria for eligibility for 'assisted dying' are flexible with variation between different jurisdictions: some have decreased safeguards initially put in place. If restricted legislation to license doctors to provide lethal drugs to patients were to be introduced, it is likely that those arguing in the UK for death-on-demand would rapidly take a test case to court to argue that such legislation was discriminatory against one group or another.

There is poor public understanding of what assisted dying is and what is involved. A 2021 survey of public understanding found that only 43% realised that assisted dying is giving lethal drugs, 42% thought incorrectly it is stopping life-sustaining treatment, 10% said hospice care and 5% didn't know.²

Drugs used

No assisted dying drug regime has been approved by any drugs regulatory authority anywhere in the world.

None of the combinations of lethal drugs used have been scientifically evaluated for ending life - the mixtures used are experimental. For assisted suicide in the USA, 100 capsules of barbiturate were initially prescribed, but shortages of barbiturates and high prices led to experimentation with different drug mixtures (diazepam, digoxin, morphine, and amitriptyline) in doses requiring around 200 tablets in total. Drug mixtures for euthanasia are similar to the cocktails injected in judicial executions, comprising a short acting anaesthetic agent (e.g. propofol) often with rocuronium which causes total paralysis, leading to death by asphyxia. Evidence from judicial executions suggests some prisoners may have regained awareness while paralysed.³

Assisted suicide is not straightforward. Oregon reports over 24 years show a 6.4% complication rate, and prolonged dying: half of patients took between 30 minutes and 104 hours to die.⁴ Nine patients re-awakened.

Role of the state

We suggest it is not appropriate for a State to provide a free death service when other services that would improve the quality-of-life are not fully state-funded.

Specialist palliative care

Palliative care in the UK remains ranked 1st in the world.⁵ Palliative Medicine has been a recognised medical specialty since 1989 in the UK, requiring four years of rigorous training. Other jurisdictions have slowly followed, but their training programmes are generally less rigorous, and in those legislatures that legalised assisted dying, the development of specialist palliative care services has been slower than in comparable countries without such legislation⁶. The exception is Switzerland where assisted dying is provided outside normal health-care services; their international ranking has risen to 13th. All other assisted dying countries' rankings have fallen since 2015, with Canada now 22nd, Belgium 26th and the USA 43rd.⁷

Across England and Wales, the level of specialist service provided is often dependent on charitable giving and unevenly integrated with local NHS services. This results in patchiness, with areas of excellence and other areas with scant community and hospital support teams, and scarce hospice-type beds. Input is therefore restricted to some people who are in the last phase of illness, which inevitably means opportunities for earlier improvement in quality of life are missed. A freedom of information request in 2016 showed that clinical commissioning groups' funding per palliative care patient per annum ranged from £52 - £2329, 78% had 7-day admission, and only 83% had 7-day community specialist services. Disease, however, respects neither the clock nor the calendar: patients need the right medication, at the right dose, at the right time for good symptom control.

There are severe workforce shortages in palliative medicine, especially in rural and deprived areas. Patients with the greatest need in our society should be a priority for public (NHS) funding and workforce development, rather than the current reliance on charitable giving to provide essential core specialist palliative care. Fundraising could then focus on all aspects of the service that allow hospices to provide additional improved environments and services for patients and families, beyond the core NHS provision.

Although proponents claim from a desktop exercise that 17 people a day die in pain (a rate lower than the complication rate in Oregon from assisted suicide), the underlying nature of their condition is unexplained. Specialist palliative care input, when available, has been shown to improve distressing symptoms more rapidly than generalist care.⁸

The "Shipman effect" resulted in GPs being cautious about prescribing morphine, and GPs generally no longer carry drugs when on home visits. Fear has also made some nurses reluctant to administer adequate opioids if the patient requires high doses. Neuropathic pain requires specialist skill, using combinations of medicines. Additionally, widespread improvement in access to pain services (for nerve blocks, or spinal analgesia) is urgently needed, as well as to single-dose palliative radiotherapy for effective pain relief of secondary bone cancer.

The variation in provision accounts for avoidable failures in care. A frequent driver behind calls for assisted suicide and euthanasia are traumatic experiences. In the Westminster Hall debate (4/7/22) 18 out of 32 listed speakers recounted such episodes, of which 6 were first-hand experience.

Crucially, evidence from the Netherlands does not show that there would be fewer bad deaths if assisted suicide and euthanasia were provided. There, authors of a 2022 study of 2786 patient records conclude ‘Symptom control at the end of life is not optimal in a substantial minority of patients. Systematic assessment and attention as well as further research on symptom management are of the essence.’⁹

Assisted dying is not an extension of palliative care. In Canada, 38.8% of patients dying by Medical Assistance in Dying (MAiD) had received palliative care (the level of input was not specified) for one month or less; additionally, some (854 in 2020) received palliative care only in the 2 weeks before death, suggesting that the MAiD request had triggered palliative care referral.^{10 11} A recent publication from Canada also reveals that “where patients had unmet needs, these were usually related to loneliness and poverty” - suffering due to society’s failure to provide for them.¹²

Participating doctors in Australia report that assisted dying fundamentally changes medical practice and is incompatible with palliative care.¹³ They report that “coordinating a VAD application through to the patient’s death equates to about sixty hours of working time”.

The priority in England and Wales must be for core specialist palliative care services to be adequately funded to ensure they are universally available, of a high standard and integrated with NHS provision so that patients can access the interventions they need for rapid symptom control and psychosocial support for them and their families, 24/7. Currently specialist palliative care support varies widely out-of-hours, with no provision in some areas, yet out-of-hours comprises over three quarters of the week.

Control and choice

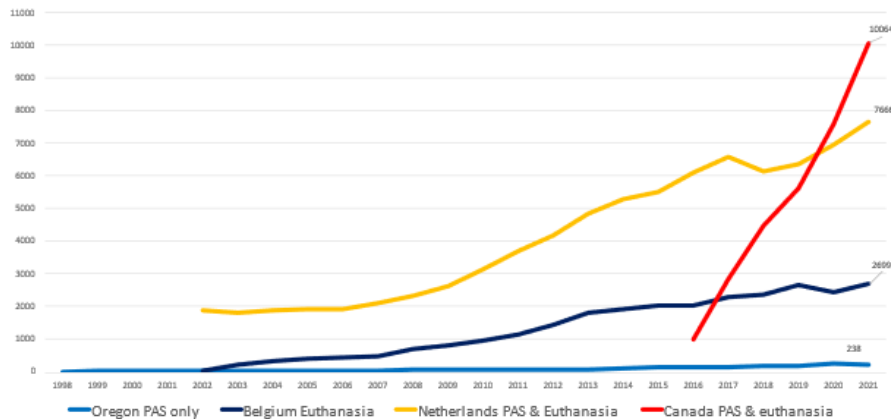
Proponents call for control and choice, yet people need real choices, not taking an action driven by despair. They need care that meets their needs and empowers them to live well.

Autonomy is not an isolated construct; we are interdependent on others for all aspects of our lives. Our autonomy is relational, hence our actions affect others across society. Cicely Saunders, founder of the modern hospice movement, defined ‘dignity’ as having a sense of personal worth and Chochinov has developed this to dignity-enhancing therapeutic approaches.¹⁴ Thus the way a person is treated by society profoundly alters their sense of dignity and worth – it is not an absolute.

Assisted Dying evidence

In ‘assisted dying’ legislation, so-called safeguards are only qualifying conditions which cannot be objectively verified with certainty. Wherever the boundaries are set, evidence from other jurisdictions shows that the boundaries are eroded and criteria expanded, with concomitant escalation in numbers, most markedly seen in Canada.

Reported assisted deaths each year (health department data for each jurisdiction)



Reporting on all aspects of ‘assisted dying’ to jurisdictions’ official monitoring bodies, although mandated, is unreliable and varies very widely, but in all of them it is post-event reporting.¹⁵ Reporting by doctors seems to drop over time. In 2010, 23% of Dutch euthanasia deaths¹⁶ and up to 50% of Belgian euthanasia deaths were unreported.¹⁷ The Belgian “unreported cases were generally dealt with less carefully than reported cases”.¹⁷ There are risks that pressured UK doctors would similarly underreport over time.

The data collected in different jurisdictions varies widely, with gaps in data.¹⁸ Oregon’s reports are destroyed after one year, impeding retrospective audit. However, in all jurisdictions there is only post-event reporting by a doctor. This lack of real-time monitoring of assessments means that evaluation of how they were conducted is impossible. Such doctor-only reporting carries risks of bias, short-cuts in assessment processes with undue influence by the clinician.

Inevitably, criteria that include some people but exclude others are open to legal challenge on grounds of inequity. This has been seen in Canada where MAiD has rapidly and controversially expanded.

Criteria proposed or in use for assisted dying

Prognosis

Defining ‘terminal illness’ is fraught with error. A prognosis of six months life expectancy is notoriously inaccurate and a ‘probabilistic art’.^{19 20 21}

The House of Lords Select Committee on the Assisted Dying for the Terminally Ill Bill chaired by Lord Mackay of Clashfern heard:

- “It is possible to make reasonably accurate prognoses of death within minutes, hours or a few days. When this stretches to months, then the scope for error can extend into years” – Royal College of General Practitioners
- “Prognosticating may be better when somebody is within the last two or three weeks of their life. I have to say that, when they are six or eight months away from it, it is actually pretty desperately hopeless as an accurate factor”- Professor John Saunders, Royal College of Physicians

A specified ‘prognosis’ in legislation will inevitably result in many people ending their lives very early in the mistaken belief that death is far closer than it is. A guestimate of prognosis is not a safeguard; experience from the Liverpool Care Pathway found no tools are sensitive enough to identify reliably

those who will die within hours or days, let alone months.²² Canada removed their “reasonably foreseeable” death criterion because of the vague nature of prognostication.

In Oregon, several people (3.8% in 2019) who were prescribed drugs for physician assisted suicide outlived their 6-months prognosis, but there may have been many more if they had not ingested lethal drugs.²³

The House of Lords Select Committee also heard that post-mortem evidence showed around 1 in 20 patients had died from a condition different to that recorded on the death certificate.²⁴

Suffering

Suffering, like fear, is an individual experience that cannot be quantified or independently assessed. The notion of “unbearable suffering” is self-determined by the person. Suffering is not inherently linked to a condition but to an individual’s subjective experience of a given condition, influenced by many social, psychological, emotional, and existential factors including the attitude of those providing care. It is not possible to assess prospectively if the subjective experience of suffering can or cannot be alleviated, but if a decision for an assisted death has been made based on current suffering, efforts in care to improve quality of life become abandoned, particularly in a seriously overstretched health service with severe workforce shortages.

There are many people with potentially terminal conditions that would, without treatment, lead to imminent death. For example, someone with type-1 diabetes could stop using insulin, thereby becoming eligible for assisted suicide.

Evidence from Oregon shows that inadequate pain control or concern about it was cited by 27.5% of assisted suicides but in Canada this was cited by 57.4% of MAiD recipients.^{25 26} Victoria, Australia does not collect data on the concerns of the patient. Relief of pain and other symptoms should promote a response of redoubled efforts to relieve symptoms, not the administration of life-ending drugs.

Voluntariness

Coercion is particularly difficult to detect. Doctors are generally poor at detecting abuse, usually because it occurs behind closed doors in a person’s home. The charity Hourglass’ data show that 1 in 5 of those over the age of 65 have been affected by abuse, 83% of which occurs in the person’s own home. Most abuse is financial (37%), psychological (33%) or neglect (21%), with victims particularly reluctant to admit their own family are harming them, rendering such abuse invisible.²⁷

Coercive forces on ill people come from internal pressures (fear of being a burden, worries over costs of care, fear of the future), often combined with external pressures such as finance.

Desire for death

Evidence from the Office for National Statistics has shown an increased rate of suicide around the time of diagnosis with a life-threatening condition. This incidence declines as disease progresses to natural death, signalling insufficient attention to mental and emotional support when a person is initially given bad news. The authors conclude, “providing better support to recently diagnosed patients is critical to help people cope with a severe condition diagnosis”.²⁸ Assisted suicide legislation has not been shown to decrease unassisted suicides.²⁹

The desire for death is known to fluctuate in patients with severe illness, chronic illness and/or despair arising from social or emotional factors – the duration is extremely variable, and relief depends on the support provided.

The side-effects of several commonly-used medications can impact a person's mental state and mental capacity, as can the direct effects of illness. For example, morphine may induce depression, and steroids often result in emotional lability, hyperactive behaviour or frank psychosis.

Around 1/3 of patients with motor neurone disease have impaired mental capacity as part of the disease process. Disturbed capacity is also seen in many other disorders, but is only detected by careful and time-consuming assessment. Many clinicians use oversimplistic tests or questions to deem a person 'compos mentis' and confuse a mini-mental-state test with capacity assessment.

Diagnosis of depression is difficult – and often missed – in those with advanced illness.^{30 31} Ganzini found that 1 in 6 people requesting assisted suicide had an untreated, reversible depression.³² This number rose to 1 in 3 amongst those who then ingested lethal drugs to end their lives.

Conscientious objection

An individual doctor, staff member at any grade or a hospice, hospital, or care home must be under no obligation to participate in any part of an assisted dying process, without prejudice for promotion or employment against such a person or funding of an organisation for refusing to participate.³³ Such provision for refusal to participate on any grounds must also apply to other professionals such as the judiciary. Other patients may be distressed when aware that a nearby patient is awaiting or is having assisted suicide or euthanasia.

If an 'Assisted Dying Service' is deliberated, its workforce should comprise only those who have opted-in to the service. All processes must protect against doctor-shopping.

Conclusion

Proponents of 'assisted dying' make assisted dying sound as if it is a well-researched, well-established medical intervention. This is not the case. So-called 'safeguards' are in fact only vague eligibility criteria. The dangers are evident in the data from the few legislatures that have reported experience in practice.

Individual cases of inadequate care, fear and distress evoke sympathy, but the answer to bad care is not for the State to provide death on demand. Licensing doctors to provide lethal drugs against imprecise and unverifiable criteria is fundamentally unsafe. The current law has shown it is compassionate in interpretation, requiring citizens to be accountable for exceptional actions, and is not need of change.

Palliative care in England and Wales needs secure financial support and workforce expansion. Patients need access to appropriate support 24/7 to meet their needs to enable them to live well. Delays in accessing medication, equipment and advice are unacceptable. We urge the Committee to rectify shortfalls in current NHS provision rather than contemplating diverting time and resources away from this duty to protect all.

Living and Dying Well

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