

HSC call for evidence for inquiry in assisted dying Jan 2023

A submission by the Association for Palliative Medicine of Great Britain and Ireland

The Association for Palliative Medicine of Great Britain and Ireland (APM) is one of the world's largest representative bodies of medical and other healthcare professionals practicing or interested in palliative care, with a membership of over 1,200. These are individuals who specialise in caring for people with a life-limiting illness, including those at the end of their life.

1. To what extent do people in England and Wales have access to good palliative care?

What is good palliative care

The active holistic care of patients with advanced, progressive illness. Management of pain and other symptoms and provision of psychological, social and spiritual support is paramount. The goal of palliative care is achievement of the best quality of life for patients and their families. Many aspects of palliative care are also applicable earlier in the course of the illness in conjunction with other treatments. (NICE 2004)

What is the evidence that we need Specialist Palliative Care for good palliative care?

Generalist palliative care is delivered by all health-care professionals working with patients with a potentially life-limiting illness, including those at the end of their life. Growing evidence supports the effectiveness and cost-effectiveness of specialist palliative care (care provided by clinicians dedicated to and expert in palliative and end-of-life care). Patients receiving early specialist palliative care show improvement in a range of outcomes including physical symptom control (Zimmerman 2014; Higginson 2014), survival (Higginson 2014; Temel 2010; Bakitas 2015), and quality of life (Zimmerman 2014; Temel 2010; Bakitas 2009), while carers express increased satisfaction (Zimmerman 2014) and decreased depression (Bakitas 2015). Early specialist palliative care can also save significant amounts of money in the health service (Smith 2014), especially for patients with multimorbidity (May 2019). There is strong evidence that specialist palliative care can contribute to meeting the goal of reducing acute unplanned hospital admissions. Indeed, specialist palliative care is one of the few interventions that has been shown to successfully enable individuals to remain in their usual residence, and potentially reduce burdensome transition to acute services (Imison 2017).

To what extent do people in England and Wales have access to good palliative care?

Access to palliative care is inadequate in England and Wales. Population based estimates suggest 69-82% of dying people in England and Wales will need access to palliative care

services (Murtagh 2014). However, this figure is growing as the number of people who are dying from conditions which are likely to require palliative care are growing (Etkind 2017). Only half of these people will receive care from specialist palliative care services and an estimated 26% receive no palliative care at all (Sue Ryder 2021).

Inadequate access to care is mirrored by inadequate quality of care at the end of life. The VOICES bereaved relative survey, last run in 2015, demonstrated that 25% of bereaved relatives felt that the care of their loved one in the last three months had been fair or poor (VOICES 2015). The National Survey for Care at the End of Life (NACEL) report for England and Wales in 2021 shows that this has not dramatically changed with 22% of bereaved relatives rating the care given to the person that died as fair or poor (NACEL 2021).

Access to palliative care varies by geography (Chukwusa 2019), by the time of day and by patient demographics including ethnicity and socioeconomic status (Davies 2019, Sleeman 2021, Tobin 2022)). The current picture is very fragmented with some patients having access to a gold standard service round the clock, while others have much more limited provision and access. The recently published Mind The Gaps report (Marie Curie 2022) illustrates this with a very poignant quote from the daughter of a dying patient: “You are guaranteed a better death if you die between 9am and 5pm Monday to Friday, so I’ve asked my mum if this would be possible... just because you would have access to the people you need.”

We know that currently there are unmet symptom needs experienced by dying patients. A study by the Office of Health Economics (Zamora 2019) found significant pain burden for patients, particularly those cared for at home:

“In England, an estimated 378,427 people receive palliative care each year in a range of specialised and generalised services... This study estimates that currently there are approximately 125,971 patients at the end-of-life receiving, or in need of, palliative care who are suffering from unrelieved pain. Of these, an estimated 16,130 patients experience no relief from their pain at all in the last three months of life. Some of these patients suffer unnecessarily because of variations in the quality of care across care settings (e.g. hospice versus at home services).”

At the current time, most people dying at home cannot even get access to the 24/7 care required to meet their most basic care needs. This not only leads to patients dying without their physical and psychological needs being met, but also sends powerful social messages about how little we value the most frail and dependent people in society. Improvements in palliative and end of life care should take a holistic public health approach as well articulated in a recent Lancet editorial (Milles et al).

- Bakitas et al. Effects of a palliative care intervention on clinical outcomes in patients with advanced cancer: the Project ENABLE II randomized controlled trial. *JAMA*. 2009;302(7):741–9.
- Bakitas et al. Early versus delayed initiation of concurrent palliative oncology care: patient outcomes in the ENABLE III randomized controlled trial. *J Clin Oncol*. 2015;33(13):1438–45.

- Chukwusa et al. Urban and rural differences in geographical accessibility to inpatient palliative and end-of-life (PEoLC) facilities and place of death: a national population-based study in England, UK. *Int J Health Geogr* 18, 8 (2019). <https://doi.org/10.1186/s12942-019-0172-1>
- Davies et al. (2019) Socioeconomic position and use of healthcare in the last year of life: A systematic review and meta-analysis. *PLOS Medicine* 16(4): e1002782. <https://doi.org/10.1371/journal.pmed.1002782>
- Etkind, et al. How many people will need palliative care in 2040? Past trends, future projections and implications for services. *BMC Med* 15, 102 (2017).
- Higginson et al. An integrated palliative and respiratory care service for patients with advanced disease and refractory breathlessness: a randomised controlled trial. *Lancet Respir Med*. 2014;2(12):979–87.
- Imison et al. Shifting the balance of care: great expectations. Nuffield Trust; 2017.
- Marie Curie. Mind The Gaps; understanding and improving out-of-hours care for people with advanced illness and their informal carers. 2022 [better-end-of-life-report-2022.pdf](https://www.mariecurie.org.uk/better-end-of-life-report-2022.pdf) ([mariecurie.org.uk](https://www.mariecurie.org.uk))
- May et al. Economics of Palliative Care for Hospitalized Adults With Serious Illness: A Meta-analysis. *JAMA Intern Med*. 2018 Jun 1;178(6):820-829. doi: 10.1001/jamainternmed.2018.0750. PMID: 29710177; PMCID: PMC6145747.
- Mills et al. Access to palliative care: the primacy of public health partnerships and community participation. *The Lancet Public Health*. 2021.
- Murtagh et al. How many people need palliative care? A study developing and comparing methods for population-based estimates. *Palliative Medicine*. 2014;28(1):49-58.
- NACEL - National Audit of Care at the End of Life. NHS Benchmarking. Report for England and Wales 2021. [NACEL Audit Outputs — NHS Benchmarking Network](https://www.nhs.uk/what-we-do/our-services/nacel-audit-outputs-nhs-benchmarking-network)
- National Institute of Clinical Excellence 2004 [Definition | Background information | Palliative care - general issues | CKS | NICE](https://www.nice.org.uk/guidance/CG140)
- Smith et al. Evidence on the cost and cost-effectiveness of palliative care: a literature review. *Palliat Med*. 2014;28(2):130–50.
- Sue Ryder Modelling demand and costs for palliative care services in England 2021
- Temel et al. Early palliative care for patients with metastatic non-small-cell lung cancer. *N Engl J Med*. 2010;363(8):733–42.
- Tobin et al Hospice care access inequalities: a systematic review and narrative synthesis *BMJ Supportive & Palliative Care* 2022;12:142-151.
- VOICES National survey of bereaved people England, 2015 [National Survey of Bereaved People \(VOICES\) - Office for National Statistics \(ons.gov.uk\)](https://www.ons.gov.uk/people-population/death-and-dying/voices-national-survey-of-bereaved-people-england-2015)
- Zamora et al , 2019. Unrelieved Pain in Palliative Care in England.
- Zimmermann et al. Early palliative care for patients with advanced cancer: a cluster-randomised controlled trial. *Lancet*. 2014;383(9930):1721–30.

a) How can palliative care be improved, and would such improvements negate some of the arguments for assisted dying/assisted suicide?

Palliative care could be improved by having sufficient resources to address issues in all those with current unmet palliative care needs. This would require additional staffing and funding for services.

It could be improved by additional education and development of generalists in programmes which make a difference to behaviour such as experiential learning or high-fidelity simulation training.

Palliative care should be available, coordinated and accessible to the whole population at all times including out of hours.

Specialist Palliative Care has received insufficient funding with charitable fundraising commonly required to support specialist palliative care staffing and facilities. There continues to be a clear lack of prioritisation of palliative and end of life care in UK government Health policy documents (Sleeman 2021).

There is evidence that good attention to symptom control and psychological support reduces requests for assisted dying (Radbruch 2016). Palliative care interventions, including management of depression, significantly reduce the proportion of patients who proceed to an assisted death (Ganzini 2000; Breitbart 2010). In addition, wider improvements in how society treats those with serious and life-limiting illnesses would improve the dignity, autonomy and sense of self-worth of those living with these conditions - and so address the main reasons why people seek an assisted death. By contrast, requiring doctors to provide assistance to end life for a similar patient with a life-limiting illness or disability would do the opposite especially when we expect doctors to do everything possible to prevent the suicide of a patient without a life-limiting illness or disability.

- Breitbart et al. Impact of treatment for depression on desire for hastened death in patients with advanced AIDS. *Psychosomatics*. 2010;51(2):98–105.
- Ganzini et al. Physicians' experiences with the Oregon Death with Dignity Act. *N Engl J Med*. 2000;342(8):557–63.
- Radbruch et al Board Members of EAPC, (2016). Euthanasia and physician-assisted suicide: A white paper from the European Association of Palliative care. *Palliative Medicine*, 2, 104–116.
- Sleeman et al. Priorities and opportunities for palliative and end of life care in United Kingdom health policies: a national documentary analysis. *BMC Palliat Care* 20, 108 (2021). <https://doi.org/10.1186/s12904-021-00802-6>

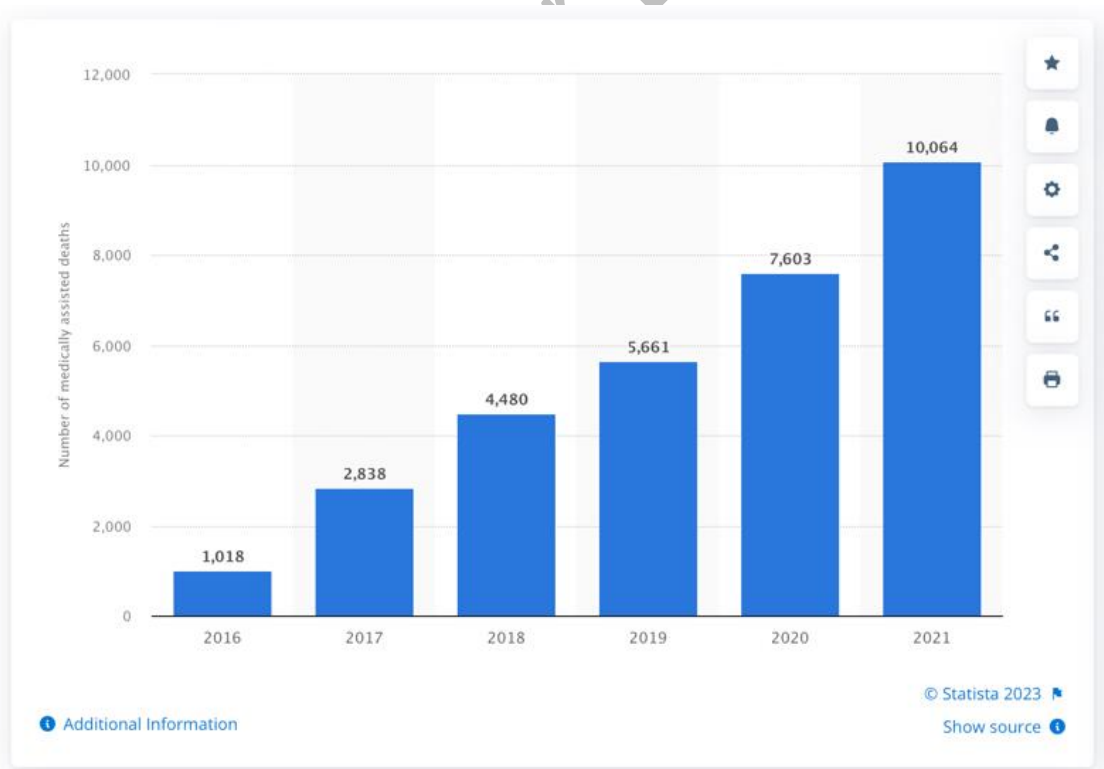
2. What can be learned from the evidence in countries where assisted dying/assisted suicide is legal?

In learning from other jurisdictions which have legalised assisted suicide/dying, we would like to draw your attention to:

- a. Numbers of assisted dying cases are increasing
- b. Eligibility criteria are being changed after legalisation
- c. There are inconsistencies in monitoring and reporting
- d. There may be an impact on palliative care services
- e. There is a lack of specialist assessment of suicidal ideation and impact on suicide prevention
- f. There is evidence of a lack of effectiveness of other safeguards
- g. There is a lack of evidence about drugs used
- h. There is evidence of euthanasia without explicit consent
- i. There is an impact on health care professionals, including moral distress

a) Assisted dying cases are increasing

Number of medically assisted deaths in Canada from 2016 to 2021



In Canada, where assisted suicide and euthanasia are legal, official statistics (MAiD report 2021) report 10,064 assisted dying provisions (3.3% of all deaths in Canada) in 2021. Assisted deaths have risen nearly 10-fold in 6 years and increased by 32% in the last year.

This increase is demonstrated in all legal jurisdictions and has never plateaued or stabilised anywhere. This includes the examples of:

Belgium and the Netherlands assisted dying has increased by 3.8 times in the last decade – 2008 to 2021 (EIB 2012), with assisted dying accounting for 1 in 25 of all deaths (Arias-Casais 2020). The true figure may be different – an estimated 48% of assisted dying cases are unreported (Smets 2010).

Assisted deaths in Oregon have more than quadrupled in the last 10 years (Oregon Death with Dignity report 2021).

- Arias-Casais N et al, Trends analysis of specialized palliative care services in 51 countries of the WHO European region in the last 14 years. *Palliative Medicine*, 2020; 34(8): 1044-56.
- European Institute of Bioethics. Euthanasia in Belgium 10 years on. 2012 <https://www.ieb-eib.org/ancien-site/pdf/20121208-dossier-euthanasia-in-belgium10-years.pdf>
- MAiD 3rd Annual Report 2021.
- Oregon Death with Dignity Act 2021 Data Summary [Internet]. Oregon Health Public Health Division; 2021. (Cited 10/11/22) Available from: <https://www.oregon.gov/oha/PH/PROVIDERPARTNERRESOURCES/EVALUATIONRESEARCH/DEATHWITHDIGNITYACT/Documents/year24.pdf>
- Smets T et al. Reporting of euthanasia in medical practice in Flanders, Belgium: cross sectional analysis of reported and unreported cases. *BMJ*, 2010; 341: c5174.

b) Eligibility criteria are changing

Once legislation is enacted, the eligibility criteria can be quickly changed – there is evidence of this occurring in Canada for example and at speed. Changes happen predominantly through the courts on the basis of equality of access and involve widening access to include those with mental health issues, children, those not terminally ill and those with self-defined suffering.

For example, in Canada, a legal challenge was mounted to the limitation that people must have a life limiting illness just two weeks following the Royal Assent of the Canadian Medical assisted in dying Bill (MAiD). This original Bill had a restriction on MAiD to people with 'grievous and irremediable suffering' and '6 months or less' prognosis, both of which, in its 6 year life span, have been removed from the legislation. In 2021 the 'reasonably foreseeable death' requirement was also removed with further legislation predicted pushing for certain mental health reasons to be included as eligible.

Belgium and the Netherlands have changed their laws to allow for assisted suicide/dying of some minors with terminal illness. The Netherlands also now allows assisted suicide/dying for newborn babies with terminal illness and perceived suffering and has now extended this to include children aged 1 to 12 years. Belgium allows assisted dying for children of all ages.

This is often called the 'slippery slope' argument (Shariff 2012) and was well illustrated by Baroness Butler-Sloss in a letter to the Times 2012; *"Laws are like nation states. They are more secure when their boundaries rest on natural frontiers. The law that we have rests on just such a frontier. It rests on the principle that we do not involve ourselves in deliberately bringing about other people's deaths. Once exceptions are introduced, based on arbitrary criteria such as terminal illness, those frontiers get blurred. They become no more than lines in the sand, hard to define and easily crossed.* (Baroness Butler-Sloss 2012).

- Baroness Elizabeth Butler-Sloss, former President of the Family Division of the High Court, The Times 5 January 2012.
- Shariff MJ. Assisted death and the slippery slope-finding clarity amid advocacy, convergence, and complexity. *Curr Oncol.* 2012 Jun;19(3):143-54.

c) Inconsistencies in monitoring and reporting

There are significant gaps and inconsistencies in reporting of assisted dying, with many jurisdictions not reporting data that could be valuable to understanding safety of assisted dying. (Worthington 2022)

In the Netherlands, monitoring committees meet when a failure of due care is identified, with focus on procedure rather than reviewing the decision to enact assisted dying (Miller 2017). There is little or no monitoring of the death itself and any data is provided by the prescriber of the lethal drugs.

In Belgium, only around 50% of cases of assisted deaths were reported in 2007 (Smets 2010).

In Oregon in 2020, information on complications was missing in 71% of assisted deaths (Oregon Death with Dignity Act Annual Reports 2020). There are unofficial reports of vomiting and prolonged deaths.

Possible explanations for the lack of reporting of cases include not considering it necessary to report or wanting to avoid the administrative burden of reporting or belief that the legal criteria were not met (Smets 2010; Cohen 2018; Onwuteaka-Philipsen 2012).

It is also worth noting that although reports indicate a high proportion of people who have assisted suicide / dying receive palliative care, there is no information on what this actually means. For example, the information on receipt of palliative care by people who have assisted suicide / dying is included in less than one-half of reports, with none providing information on the duration or scope of hospice or palliative care involvement.

Furthermore, while reports indicate that 80-90% of Canadian assisted deaths received palliative care, more in-depth studies have shown that fewer than half of patients had seen a specialist palliative care team. (Worthington 2022)

- Cohen et al. (2018). How accurately is euthanasia reported on death certificates in a country with legal euthanasia: a population-based study. *Eur. J. Epidemiol.*, Vol 33, 689–693.
- Miller et al. Euthanasia and physician-assisted suicide not meeting due care criteria in the Netherlands: a qualitative review of review committee judgements *BMJ Open*, 2017; 7(10): e017628.
- Onwuteaka-Philipsen et al. (2012). Trends in end-of-life practices before and after the enactment of the euthanasia law in the Netherlands from 1990 to 2010: a repeated cross-sectional survey. *The Lancet*, Vol 380, 908–915.
- Oregon Death with Dignity Act: annual reports; 2020. Data Summary [Internet]. Oregon Health Public Health Division: 2020. (Cited 10/11/22) Available from: <https://www.oregon.gov/oha/PH/PROVIDERPARTNERRESOURCES/EVALUATIONRESEARCH/DEATHWITHDIGNITYACT/Documents/year23.pdf>
- Smets et al. (2010). Reporting of euthanasia in medical practice in Flanders, Belgium: cross sectional analysis of reported and unreported cases. *BMJ*, Vol 341, c5174.
- Worthington et al. Comparison of official reporting on assisted suicide and euthanasia across jurisdictions. *BMJ Support Palliat Care*. 2022 Dec 30:spcare-2022-003944. doi: 10.1136/spcare-2022-003944. Epub ahead of print. PMID: 36585221.

d) Impact on palliative care services

In Belgium and the Netherlands between 2012 and 2019, growth stalled in home care, hospital and inpatient palliative care services. (Arias-Casais 2020). Of 51 European countries, increased growth in palliative care services occurred in only 30, with the most significant growth in 18, none of which had legalised assisted dying. (Arias-Casais 2020).

In Oregon, legalisation was followed by an increase in severe untreated pain among terminally ill patients. During a period when 1,832 hospices opened in other states, only five opened in Oregon (Ballentine 2016). In other states legalising assisted suicide, use of hospice care has fallen below the national average (Shen 2015).

A Palliative Care doctor in the Netherlands, reported that assisted dying “becomes a substitute for learning how to relieve the suffering of dying patients.” (Zylicz 2022).

In Canada, interviews with palliative care staff revealed significant impacts on their work including challenges with symptom control, challenges with communication and impacts on relationships with patients; and the consumption of palliative care resources to support assisted death (Mathews 2020). The availability of assisted dying has also impacted on end-of-life care discussions, and the therapeutic value of these conversations: “*the ability to help people deal with their existential crisis through talking and reflection is severely constrained*”. (Ho 2021)

However others report no adverse impact on palliative care services or that there had been advancement of palliative care services. (Palliative Care Australia 2018).

- Arias-Casais et al. *Palliative Medicine*, 2020; 34(8): 1044-56.
- Ballentine et al., “Physician-Assisted Death Does Not Improve End-of-Life Care,” *Journal of Palliative Medicine* 19 (2016): 1-2. Ho et al. *Palliative Care and Social Practice*. 2021; 15: 1-14
- Mathews et al. Impact of Medical Assistance in Dying on palliative care: A qualitative study. *Palliative Medicine*. 2021;35(2):447-454. doi:[10.1177/0269216320968517](https://doi.org/10.1177/0269216320968517)
- Palliative Care Australia 2018 Experience internationally of the legalisation of assisted dying on the palliative care sector FINAL REPORT [Aspex Consulting Report \(palliativecare.org.au\)](https://www.palliativecare.org.au)

- Shen et al, *Suicides in Oregon: Trends and Associated Factors. 2003-2012* (Oregon Health Authority 2015);
- Zyllicz. *Palliative Care and Euthanasia in the Netherlands. In The Case Against Assisted Suicide*, 142. Baltimore and London: Johns Hopkins University Press.

e) Specialist assessment of suicidal ideation and suicide prevention

In Canada only 6.7% of 10,064 assisted dying provisions (3.3% of all deaths in Canada) were referred to a psychiatrist for assessment in 2021 (Medical assistance in Dying in Canada 2021). In Oregon in 2021, only 2 patients out of 383 were referred for psychiatric evaluation (0.5%) (Oregon Death with Dignity Act 2021). In 2020 this was only 1 patient out of 188 (Oregon Death with Dignity report 2020). Three quarters of those requesting assisted suicide report being lonely and 60% are clinically depressed (Hartog 2020). It seems that mental health assessment is being missed, which could identify depression as a trigger for assisted dying request in these patients.

In the Netherlands, an analysis of individuals requesting euthanasia or assisted suicide for mental health issues showed that the commonest diagnosis was a depressive mood disorder and that, compared with the general population, they were more likely to be single, female, or a lower educational background and with a history of sexual abuse (Kammeraat 2019).

Diagnosis of severe physical health conditions is associated with an increased risk of dying by suicide, especially immediately after diagnosis (Nafilyan 2022). In Oregon, the background suicide rate has risen by nearly one third (32%) since 'assisted suicide' was legalised (Oregon HAPHD 2021; CDC 2022). There is no reduction – and sometimes an increase – in non-assisted suicide, compared to neighbouring European countries suggesting legalising assisted dying may change public behaviours around suicide (Jones 2022). This is supported by Belgium having the highest non-assisted suicide rate in women in Europe (Jones 2022).

This is all despite evidence that the provision of symptom control, timely detection and intervention for depression coupled with a focus on optimising function, instilling hope and preserving dignity help alleviate any wish to hasten death in patients with advanced illness. (Price 2011).

- Centre for Disease Control and Prevention (CDC) Suicide Mortality by State. 2022 [Internet] National Centre for Health Statistics, Suicide Mortality by State. (Cited 10/11/22) Available from: <https://www.cdc.gov/nchs/pressroom/sosmap/suicide-mortality/suicide.htm>
- Hartog et al. Prevalence and characteristics of older adults with a persistent death wish without severe illness: a large cross sectional survey. *BMC Geriatrics*. 2020; 20(1): 342-56
- Jones. Euthanasia, assisted suicide and suicide rates in Europe. [Internet]. *J Euthan Ment Health*. 2022;11:1-35. (cited 2022 Feb 12). Available from: <https://jemh.ca/issues/open/documents/JEMH%20article%20EAS%20and%20suicide%20rates%20in%20Europe%20-%20copy-edited%20final.pdf>
- Kammeraat et al. Psychiatrische patiënten bij Expertisecentrum: Euthanasie. [Internet]. Den Haag, Netherlands: 2019. (cited 2021 Dec 21). Available from: <https://www.eumonitor.eu/9353000/1/j9vvik7m1c3gyxp/vl69rglw8cyv>

- Medical assistance in Dying in Canada 3rd annual report [Internet]. Ottawa, Canada: Health Canada;2021 (cited 10/11/22) Available from: <https://www.canada.ca/en/health-canada/services/medical-assistance-dying/annual-report-2021.html>
- Nafilyan et al. Risk of suicide after diagnosis of severe physical health conditions: A retrospective cohort study of 47 million people <https://doi.10.1016/j.lanepe.2022.100562>
- Oregon Death with Dignity Act 2021 Data Summary [Internet]. Oregon Health Public Health Division; 2021. (Cited 10/11/22) Available from: <https://www.oregon.gov/oha/PH/PROVIDERPARTNERRESOURCES/EVALUATIONRESEARCH/DEATHWITHDIGNITY/CT/Documents/year24.pdf>
- Oregon Death with Dignity Act 2020 Data Summary [Internet]. Oregon Health Public Health Division: 2020. (Cited 10/11/22) Available from: <https://www.oregon.gov/oha/PH/PROVIDERPARTNERRESOURCES/EVALUATIONRESEARCH/DEATHWITHDIGNITY/CT/Documents/year23.pdf>
- Oregon Health Authority Public Health Division. [Internet]. Oregon Health Public Health, Oregon Violent Death Division: 2021 (Cited 10/11/22) Available from: <https://www.oregon.gov/oha/PH/DiseasesConditions/InjuryFatalityData/Pages/nvdrs.aspx>
- Price et al. Prevalence, course and associations of desire for hastened death in a UK palliative population: a cross-sectional study. *BMJ Support Palliat Care*. 2011 Sep;1(2):140-8. doi: 10.1136/bmjspcare-2011-000011. Epub 2011 Jul 4. PMID: 24653226.

f) Effectiveness of safeguards

Adequate assessment and treatment of physical and other symptoms

The presence of uncontrolled pain was a factor influencing requests for assisted dying in 44% of euthanasia requests in Belgium (Heijltjes 2020). Half of patients requesting assisted suicide under the Oregon law in its first three years changed their minds when the doctor provided palliative care [Verkerk 2009].

However, the desire to hasten death is often influenced by emotional distress and suffering as opposed to uncontrolled physical symptoms. A profile of patients in receipt of assisted suicide in Oregon (Ganzini 2009) report the following issues as main motivations for seeking a hastened death namely: reduced ability to engage with activities to enjoy life (90.4%); loss of autonomy (86.7%); loss of dignity (72.3%) and feeling a burden on family, caregivers or friends (59%). Data from Canada suggests that the duration of palliative care input is very short prior to before assisted dying – 37.1% of patients receiving palliative care for less than a month – and this may not be sufficient time for symptoms to be controlled (MAiD 2020). No jurisdiction has designed safeguards that would protect people from these psychological factors being the driving force for seeking assisted dying.

Pressure on those with advanced illness/disability to request an assisted death.

Experience from other countries demonstrates how legalising assisted dying for those with life-limiting illnesses or disabilities can lead to eligible patients feeling pressurised, either directly or indirectly, to request an assisted death. In Oregon, there have been progressive increases in both the number and proportion of patients who chose an assisted death due to concerns about loss of dignity and feeling like a burden on others (Seale 2015; Oregon Death with Dignity Reports 2020).

The UN special rapporteur on the rights of persons with disabilities has documented concerns about people with severe illnesses/disabilities in Canada being offered an assisted death rather than having their care needs met (UN 2019), and explicit and well-documented examples of this practice are mounting (Canadian Standing Committee 2022). This is in direct contradiction to the claim by campaigners in favour of medically assisted dying that legalising medically assisted dying would reduce illegal and unregulated assisted dying.

Cooling off period

There is clear evidence that the desire to hasten death is highly unstable in patients with advanced and terminal illness, with as many as half changing their minds during follow-up (Emanuel 2000), including those with “a long-lasting and apparently consolidated wish to hasten death,” (Ohnsorge 2014) and with important changes seen even in the last weeks of life (Rosenfeld 2014). Despite this, legislation has been enacted without any mandatory ‘cooling off’ period in New Zealand, and the reflection period has been removed in Canada (Government of Canada).

- Canadian Standing Committee on Justice and Human Rights [Internet]. Available from: <https://www.ourcommons.ca/DocumentViewer/en/43-2/JUST/meeting-6/evidence> Available from: <https://www.ctvnews.ca/politics/paralympian-trying-to-get-wheelchair-ramp-says-veterans-affairs-employee-offered-her-assisted-dying-1.6179325>
- Emanuel et al. Attitudes and desires related to euthanasia and physician-assisted suicide among terminally ill patients and their caregivers. *J Am Med Assoc.* 2000;284(19):2460–8.
- Ganzini L et al Oregonians’ reasons for requesting physician aid in dying. *Arch Intern Med* 2009;169:489-92. doi10.1001/archinternmed.2008.579. pmid: 19273779
- Government of Canada. [Internet] Available from <https://www.justice.gc.ca/eng/cj-jp/ad-am/bk-di.html>
- Heijltjes et al. Changing practices in the use of continuous sedation at the end of life. A systematic review of the literature. *J Pain Symptom Manage.* 2020.
- Medical Assistance in Dying in Canada Second Annual Report 2020. Available from: <https://www.canada.ca/en/health-canada/services/medical-assistance-dying/annualreport-2020.html>
- Ohnsorge et al. Intentions in wishes to die: Analysis and a typology - A report of 30 qualitative case studies of terminally ill cancer patients in palliative care. *Psychooncology.* 2014;23(9):1021–6.
- Oregon Death with Dignity Act Annual Reports. [Internet]. [cited 2020 Jul 3]. Available from: <https://www.oregon.gov/oha/PH/PROVIDERPARTNERRESOURCES/EVALUATIONRESEARCH/DEATHWITHDIGNITYACT/Pages/ar-index.aspx>
- Rosenfeld et al. Does desire for hastened death change in terminally ill cancer patients? *Soc Sci Med.* 2014;111:35–40.
- Seale et al. The language of sedation in end-of-life care: The ethical reasoning of care providers in three countries. *Health.* 2015;19(4):339–54.
- United Nations Human Rights Office of the High Commissioner. End of Mission Statement by the United Nations Special Rapporteur on the rights of persons with disabilities, Ms. Catalina Devandas-Aguilar, on her visit to Canada. Ottawa, 12 April 2019. [Internet]. [cited 2020 Feb 12]. Available from: <https://www.ohchr.org/en/NewsEvents/Pages/DisplayNews.aspx?NewsID=24481&LangID=E>
- Verkerk et al. Guideline for Palliative Sedation Royal Dutch Medical Association (KNMG) [Internet]. 2009 [cited 2019 Aug 13]. p. 1–78. Available from: https://palliativedrugs.com/download/091110_KNMG_Guideline_for_Palliative_sedation_2009_2_%5B1%5D.pdf

g) Lack of evidence about drugs used

The lethal drugs used in assisted suicide/dying have never been formally researched or agreed for such a purpose (Sinmyee 2019). Oregon has tried four different oral drug mixtures in the last seven years (Oregon Death with Dignity report 2021).

Opioids can be used for assisted dying. In clinical practice, fear about opioids can be a barrier to their use (Calongelo 2020). Indeed, health professionals have expressed concern that if assisted suicide / dying were legalised and opioids used, this would increase reluctance of patients to accept them for symptom control, with a potential negative impact on symptom control for patients at the end of life (Calongelo 2020).

In the Netherlands, 7% of people given access to drugs for assisted dying vomited the medication up, and 16% experienced significant problems such as failure to induce coma, or induction of coma followed by awakening of the patient or a prolonged time to die (Groenewoud 2000). It is worth noting that 99% of patients in Canada given a choice of administration chose the intravenous route for assisted dying (MAiD Report 2021).

- Calongelo et al 2020 [Spread the Word: There Are Two Opioid Crises! | SpringerLink](#)
- Groenewoud et al. Clinical problems with the performance of euthanasia and physician-assisted suicide in the Netherlands. *N Engl J Med.* 2000; 342(8): 551-6.
- MAiD 3rd Annual Report 2021.
- Oregon Death with Dignity Act 2021 Data Summary [Internet]. Oregon Health Public Health Division; 2021. (Cited 10/11/22) Available from: <https://www.oregon.gov/oha/PH/PROVIDERPARTNERRESOURCES/EVALUATIONRESEARCH/DEATHWITHDIGNITYACT/Documents/year24.pdf>
- Sinmyee et al. Legal and ethical implications of defining an optimum means of achieving assisted dying. *Anaesthesia.* 2019; 74(5): 630-7.

h) Evidence of euthanasia without explicit consent

In the Netherlands, patients have undergone euthanasia without an explicit request (Van Norman 2014). About 20% of cases have gone unreported raising questions of whether legal standards for consent are being met.

- Van Norman. 2014. Physician aid-in-dying: Cautionary words. *Current Opinions in Anesthesiology* 27: 177–82.

i) Impact on health care professionals

Participating in assisted dying has a significant emotional impact on some practitioners, including moral distress and psychological harm. (Dholakia, 2022).

- Dholakia et al. Emotional impact on healthcare providers involved in medical assistance in dying (MAiD): a systematic review and qualitative meta-synthesis. *BMJ Open* 2022;**12**:e058523. doi: 10.1136/bmjopen-2021-058523

3. What are the professional and ethical considerations involved in allowing physicians to assist someone to end their life?

The ethical considerations include:

- a) Autonomy
- b) Trust in doctors and participation of doctors in assisted dying
- c) Impact on staff and organisations, including conscientious objection
- d) Difficulties assessing capacity and identifying coercion

a) Autonomy

Whilst access to assisted dying would support the autonomy of the individual, autonomy of the person requesting assisted dying impacts on the autonomy of a wide group of people. This impact includes, but is not limited to, their family, those who are providing the assistance to die and wider groups of people, including those who are disabled and vulnerable members of society. People are interconnected and it is important to be clear that the actions of one person (e.g. person requesting or receiving assisted dying) will impact on others.

b) Trust in doctors and participation of doctors in assisted dying

Doctor involvement in assisted suicide risks damaging patient and societal trust in doctors. (Fritz 2019). There are strong arguments that assisted dying, if legalised, should take place entirely outside of medical practice (Fritz 2019).

- Fritz, Z. (2019). The courts should judge applications for assisted suicide, sparing the doctor-patient relationship.

c) Impact on staff and organisations, including conscientious objection

Ability to make a conscientious objection to participating in assisted dying would be absolutely essential. It is also essential that organisations have the ability to make a

conscientious objection. Not allowing conscientious objection risks imposing harm on health or social care practitioners (Dholakia 2022), violating their autonomy and risking an exodus of skilled and valuable health and social care practitioners (Willis 2018).

- Dholakia et al. Emotional impact on healthcare providers involved in medical assistance in dying (MAiD): a systematic review and qualitative meta-synthesis. *BMJ Open* 2022;**12**:e058523. doi: 10.1136/bmjopen-2021-058523
- Willis et al. Conscientious objection and physician-assisted suicide: a viable option in the UK? *BMJ Support Palliat Care*. 2019 Dec;**9**(4):464-467. doi: 10.1136/bmjspcare-2018-001541. Epub 2018 Nov 15. PMID: 30446490.

d) Difficulties assessing capacity and identifying coercion

Experience over 15 years with the Mental Capacity Act demonstrates a persisting problem with implementing safeguarding legislation by healthcare staff (including doctors) and organisations (House of Lords 2005; Marshall 2018; Heslop 2013). As a result, doctors and organisations cannot exclude undue influence on patients or implement safeguarding law. Doctors and other clinical staff are not specially trained to identify coercion. Judges and court process would be needed to identify coercion.

- Heslop et al. Confidential Enquiry into the Premature Deaths of People with Learning Disabilities (CIPOLD). Norah Fry Research Centre: Bristol: University of Bristol 2013. See <http://www.bristol.ac.uk/cipold/>.
- House of Lords Select committee on the Mental Capacity Act. Mental Capacity Act 2005: post-legislative scrutiny. 2005. London: The Stationery Office, 2014. See: <https://publications.parliament.uk/pa/ld201314/ldselect/ldmentalcap/139/139>.
- Marshall et al. The Mental Capacity Act: 10 years on – the key learning areas for healthcare professionals *Nursing: Research and Reviews*, 2018; 8; 29-38

4. What, if any, are the physical and mental health criteria which would make an individual eligible to access assisted dying/assisted suicide services?

Any criteria that are set could be subject to change and this is a risk to the safety of any legislation, especially to the most vulnerable people in society. Any legislation can be changed by a court proceeding, for example on the basis of equality, to expand the scope further. This opens the opportunity for expansion of any set eligibility to include minors, people with dementia or a disability and the potential for ever widening criteria. This has occurred in jurisdictions which allow assisted dying. This can be an example of the slippery slope nature of assisted dying legislation (Shariff 2012). This has happened in Canada with an extension of assisted dying legislation to cover those who cannot consent (including those with dementia) but who have made an advance request for it (Assemblée Nationale du Québec 2021).

- Assemblée Nationale du Québec 2021 Report of the select committee on the evolution of the act respecting end-of-life care.
[report_of_the_select_committee_on_the_evolution_of_the_act_respecting_end-of-life_care.pdf](#)
- Shariff MJ. Assisted death and the slippery slope-finding clarity amid advocacy, convergence, and complexity. *Curr Oncol.* 2012 Jun;19(3):143-54.

5. What protections could be put in place to protect people from coercion and how effective would these be?

It is very difficult to determine whether a decision is compromised by coercion or undue influence.

In the UK, the Mental Capacity Act 2005 stipulates the criteria that a person must meet to be deemed to have capacity to make a specific decision. Capacity is decision specific and there is always a presumption in favour of someone having capacity with the onus being on the assessor to evidence the fact that they do not. Full decision-making capacity to make such a decision is essential, but reliable and consistent capacity assessment in healthcare is complex and continues to be poorly and inconsistently practiced (Taylor 2016). There is also a lack of consensus as to what constitutes capacity for assisted suicide / dying and whether current legal frameworks are able to support clinicians in determining capacity for this group. (Price 2014).

Capacity is time, situation and decision specific and can fluctuate over time. Healthcare professionals may lack sufficient expertise and skills in assessing decision making capacity with previous international studies confirming that capacity assessment is insufficiently embedded into daily clinical practice (UK Parliament 2014; Lamont 2013; Lamont 2019; Vara 2020). As end-of-life approaches, a patient's decision-making capacity is influenced and

frequently may be compromised by illness, anxiety or depression. Patients with terminal illness are vulnerable, with a higher incidence of depression and may often experience a sense of worthlessness adding to what can be a perceived 'duty to die.'

The House of Lords select Committee and peer reviewed literature cite problems with the protection that the Mental Capacity Act offers to those who are vulnerable and may be particularly subject to the influence of others (Cave 2017; Wade 2019; Hinsliff 2017; UK Parliament 2014). This shows that even when legislation is put in place, its inconsistent implementation and/or the level or lack of skill of people implementing the legislation are insufficient to protect individuals from coercion.

- Cave 2017. [Protecting Patients from their Bad Decisions: Rebalancing Rights, Relationships, and Risk - PMC \(nih.gov\)](#) *Med Law Rev.* 25(4): 527–553. doi: [10.1093/medlaw/fww046](#)
- Hinsliff-Smith et al. What do we know about the application of the Mental Capacity Act 2005 in healthcare practice regarding decision-making for frail and older people? A systematic literature review. *Health Soc Care Comm* 2017; 25(2): 295–308.
- Lamont, et al. Health care professionals' knowledge, attitudes and behaviours relating to patient capacity to consent to treatment: an integrative review. *Nurs Ethics* 2013; 20: 684–707.
- Lamont et al, Capacity and consent; Knowledge and practice of legal and healthcare standards *Nurs Ethics* 2019; 26(1) 71-83
- Price et al. Concepts of mental capacity for patients requesting assisted suicide: a qualitative analysis of expert evidence presented to the Commission on Assisted Dying. *BMC Med Ethics.* 2014 Apr 22;15:32. doi: [10.1186/1472-6939-15-32](#). PMID: 24755362; PMCID: PMC3998063.
- Taylor HJ. What are "Best interests"? A critical evaluation of "best interests" decision-making in clinical practice. *Med Law Rev.* 2016 24(2):176-205. doi: [10.1093/medlaw/fww007](#). <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4914708/>
- UK Parliament 2014. Select committee on the Mental Capacity Act 2005. Report of session 2013-14 Mental Capacity Act 2005: post-legislative scrutiny [House of Lords - Mental Capacity Act 2005: post-legislative scrutiny - Select Committee on the Mental Capacity Act 2005 \(parliament.uk\)](#)
- Vara et al, General practitioners and decision making capacity assessment : the experience and educational needs of New Zealand general practitioners *Fam Practice* 2020; 37(4) 535-40
- Wade DT, Kitzinger C. Making healthcare decisions in a person's best interests when they lack capacity: clinical guidance based on a review of evidence. *Clin Rehab*, 2019; **33**(10): 1571-85.

6. What information, advice and guidance would people need in order to be able to make an informed decision about whether to access assisted dying/assisted suicide services?

It is not possible to answer this question in the abstract, without addressing the significant ethical issues raised by the proposed assisted dying models to date.

7. What capabilities would a person need to be able to consent to assisted dying /assisted suicide?

It is not possible to answer this question in the abstract, without addressing the significant ethical issues raised by the proposed assisted dying models to date.

8. What should the Government's role be in relation to the debate?

Given the current fragmented picture outlined in question one, the government needs to level across the UK and increase the funding overall for specialist and generalist palliative care to ensure equitable provision for patients. It cannot ever be the case that a patient should see assisted suicide / dying as their only option due to poor access to good symptom control and psychological support.

The widespread challenges with provision of adequate social care, including for people in their own homes, impacts significantly on those nearing the end of their lives. We know that psychological and social motives motivate requests for assisted suicide more than physical symptoms (Sprung 2018) and so ensuring comprehensive provision of high quality social care must also be a priority.

Finally, the Government has a legal duty under the Equality Act 2010 to protect those with protected characteristics, including disability, from discrimination.

- Sprung et al. 2018. Physician-Assisted Suicide and Euthanasia: Emerging Issues From a Global Perspective. *J Palliat Care*, 33(4), 197-203. doi: 10.1177/0825859718777325
-
-

Not For Further Research