Submission to the Isle of Man Government consultation on “assisted dying” on behalf of Care Not Killing (CNK Alliance Ltd) and Our Duty of Care

January 2023

Introduction

3. Are you responding on behalf of an organisation?

Yes

4. If you answered "yes" to the previous question please state which organisation

Care Not Killing and Our Duty of Care

Care Not Killing (CNK) is a UK-based alliance working to:

- promote more and better palliative care;
- ensure that existing laws against euthanasia and assisted suicide are not weakened or repealed;
- influence the balance of public opinion against any further weakening of the law.

Formed in 2005 to oppose Lord Joffe's Assisted Dying for the Terminally Ill Bill, CNK has since campaigned on the MacDonald and Harvie Bills at Holyrood, and the Falconer, Marris and Meacher Bills at Westminster, as well as intervening in major court cases including those of Tony Nicklinson, Noel Conway and 'Y'.

Our Duty Of Care (ODOC) is a group of UK healthcare workers who oppose the intentional killing of patients by assisted suicide or euthanasia, supported financially and administratively by CNK. Working with a wide range of healthcare professionals across the UK, ODOC has campaigned during the membership polls run by the Royal College of Physicians, Royal College of General Practitioners and British Medical Association.

5. Are you responding as an individual or a group?

Group

6. Are you resident on the Isle of Man?

No

7. May we publish your response?

Yes, you can publish my response in full

Support for Proposal

8. In principle, do you agree or disagree that assisted dying should be permitted for terminally ill adults on the Isle of Man?

Disagree

Please explain the reasons for your response

We hold that legal change to permit assisted suicide and/or euthanasia would be uncontrollable, unethical and unnecessary.

1. Uncontrollable, as we shall see, because the current law rests on a natural frontier with all forms of legalisation susceptible to escalating numbers of deaths, expansion and abuse including under-reporting.
2. Unethical owing to the effect on patients, making them feel burdensome due to the extra care and support they need, and on doctors and other healthcare professionals with conscientious objections.
3. Unnecessary because of the high quality of care Manx residents have recourse to, thanks to a comprehensive palliative care service and community support driven by families, friends, neighbours, the health and social care service and a range of charities. Hospice Isle of Man's Chief Executive and Lead Clinician have said in a statement that: 'the Isle of Man Hospice experience to date has been that request by patients even to discuss artificially hastening their death have been extremely rare on-Island" and any legislation for "assisted dying" would "undermine palliative care."[1]

There is evidence from neighbouring jurisdictions of significant public misunderstanding concerning "assisted dying".

Former Supreme Court justice Lord Sumption has observed that although law change advocates claim "the public is overwhelmingly in favour, a lot of polling evidence suggests that that rather depends on the degree of detail which goes into the asking of the question."[2] 2014 ComRes polling[3] (UK) found that respondents moved from 73%-12% in favour to 43%-43% once just a few arguments against legalisation had been heard. A July 2021 UK survey found that more than half of respondents thought the term "assisted dying" meant "providing hospice-type care to people who are dying" or "giving people who are dying the right to stop life-prolonging treatment."[4] Only 42% realised that it refers to giving lethal drugs to a patient to end their life intentionally.

The Association for Palliative Medicine (APM) published feedback[5] from a membership survey in 2022, which found that more than half of respondents (67%) said patients and families think they are definitely or probably practicing covert euthanasia:

> "Palliative care is already equivalent to euthanasia in the public's mind here – they associate syringe pumps with euthanasia and this is a myth we have to dispel on a daily basis when interacting with patients and their families in the hospital."

[1] manxradio.com/news/isle-of-man-news/mhk-supports-public-conversation-over-assisted-dying/
[2] downloads.bbc.co.uk/radio4/reith2019/Reith_2019_Sumption_lecture_1.pdf
[3] carenotkilling.org.uk/public-opinion/assisted-dying-public-opinion/
[4] dyingwell.co.uk/wp-content/uploads/2021/09/Survation-Assisted-Dying-Survey-July-2021-Summary-3.pdf
[5] apmonline.org/wp-content/uploads/2022/01/APM-Member-Survey-2021-final.pdf

Most respondents (87%) felt there has not been enough press coverage of good deaths: might the persistence of "assisted dying" advocates in fact eclipse public awareness of life-changing palliative care, to the detriment of both patients and professionals?

Throughout the rest of our submission, we will refer to "assisted suicide" (or "euthanasia", or "E&AS" where appropriate), rather than "assisted dying", a campaigning euphemism intended to cushion the reality. In 2019, the American Medical Association's Council on Ethical and Judicial Affairs (CEJA) reported[6] that:

> "Proponents of physician participation often use language that casts the practice in a positive light… However… CEJA believes ethical deliberation and debate is best served by using plainly descriptive language. In the council's view, despite its negative connotations, the term "physician assisted suicide" describes the practice with the greatest precision. Most importantly, it clearly distinguishes the practice from euthanasia. The terms "aid in dying" or "death with dignity" could be used to describe either euthanasia or palliative/hospice care at the end of life and this degree of ambiguity is unacceptable for providing ethical guidance."

The Netherlands legalised E&AS via the "Termination of Life on Request and Assisted Suicide (Review Procedures) Act"; how can any legislator justify considering legalising a practice if they can't bring themselves to describe it "with the greatest precision"?

That same CEJA report found that "physician-assisted suicide is fundamentally incompatible with the physician's role as healer, would be difficult or impossible to control, and would pose serious societal risks."

We note a worrying trend of medically eligible people applying for E&AS in Canada not because of their conditions but because of a lack of support. Recent examples include:

- 54-year-old Amir Farsoud who hit the headlines in November 2022 when he applied for MAiD because he was in danger of losing his housing and feared being made homeless[7]
- Roger Foley, who recorded a hospital employee offering him a MAiD death, citing the financial cost of his care and being unwilling to provide the care package best suited to Mr Foley[8]
- Paralympian Christine Gauthier, who applied for financial support as a veteran and was told, "if you're so desperate, madam, we can offer you MAID, medical assistance in dying"[9]

At the heart of the debate on assisted suicide is a balancing of rights and responsibilities. The compatibility of the blanket ban on assisted suicide with the European Convention on Human Rights has been repeatedly tested in the highest courts. Lord Justice Sales, Mrs Justice Whipple and Mr Justice Garnham concluded in 2017 that:

> 'It is legitimate in this area for the legislature to seek to lay down clear and defensible standards in order to provide guidance for society, to avoid distressing and difficult disputes at the end of life and to avoid creating a slippery slope leading to incremental expansion over time of the categories of people to whom similar assistance for suicide might have to [be] provided… we find that section 2 [of England & Wales' Suicide Act,

[6] ama-assn.org/system/files/2019-05/a19-ceja2.pdf
[7] toronto.citynews.ca/2022/10/13/medical-assistance-death-maid-canada/
[8] dyingwell.co.uk/stories/roger-foley/
[9] independent.co.uk/news/world/americas/christine-gauthier-paralympian-euthanasia-canada-b2238319.html

containing essentially the same provision as the Isle of Man's] is compatible with the Article 8 rights [private and family life]."[10]

9. Do you think that there should be a limit on their life expectancy?

We decline to answer

10. Do you support the provision of assisted dying for someone who has a condition which causes unbearable suffering that cannot be alleviated by other means but which may not give a terminal diagnosis?

No

11. If they are unable to take oral medication should a health care professionally be permitted to administer medication intravenously to achieve death?

No

Eligibility

12. Do you agree that assisted dying should be available only to people over the age of 18 Years?

We decline to answer

13. Should they have to be permanent residents of the Isle of Man?

Yes

14. If you agree they should be permanent residents please state for how long.

We decline to answer

Process

15. Do you agree with the proposal that two different doctors should meet with the person independently and establish they are mentally competent to make an informed decision without pressure or coercion?

We decline to answer

16. Should any health professional be able to conscientiously object to being part of an assisted dying programme?

Yes

[10] carenotkilling.org.uk/articles/appeal-judges-dismiss-conway-bid/
judiciary.uk/wp-content/uploads/2017/10/r-conway-v-ssj-art-8-right-to-die-20171006.pdf

17. Do you agree that if either doctor is unsure about the person’s capacity to request an assisted death, the person should be referred to a psychiatrist for a further capacity assessment?

Yes

18. Do you agree that the two doctors should ensure that the person has been fully informed of palliative, hospice and other treatment and care options?

Yes

19. Do you support the proposal that the person signs a written declaration of their request, which is witnessed and signed by both doctors?

We decline to answer

20. Do you agree that there should be a waiting period of 14 days from this time to the provision of life ending medication to allow the person to reconsider their decision?

We decline to answer

21. Do you feel that this period should be shortened to 7 days if the person is expected to die within 30 days?

No

22. Should the person themselves or a relative be able to collect the relevant medication from a designated pharmacist?

No

23. Should this be able to be stored securely in the person’s home until they decide whether they want to take it or not?

No

24. If they change their mind should the medication be returned to the pharmacy immediately?

We decline to answer

25. Should a health care professional be required to be with the patient once they have taken the medication until they are certified to have died?

We decline to answer

26. Should an annual report be produced regarding the number of people who have taken advantage of assisted dying, and be published?

Yes

27. Should it be possible to include the provision of assisted dying in a "living will" or advanced directive?

No

28. Do you have any comments on the process to provide Assisted Dying which will be included in the draft Bill

Eligibility (Qs 9, 10, 12, 13 & 14)

The Oregon model has been central to efforts to legalise assisted suicide across the British Isles: terminally ill, adult residents who doctors expect to die within six months. Disability rights campaigner Baroness Campbell of Surbiton, who is living with spinal muscular atrophy, has said of such proposals in Westminster:

> "The [present] law [in England & Wales[11], which was almost identical[12] to the offence contained within the Isle of Man's Criminal Law Act 1981[13]] combines deterrence with discretion… [and] rests on a natural frontier. It rests on the principle that we do not involve ourselves in deliberately bringing about the deaths of other people. What the proponents of "assisted dying" want is to replace that clear and bright line with an arbitrary and permeable one… If terminal illness, why not chronic and progressive conditions? And, if chronic and progressive conditions, why not seriously disabled people? I am already on the list."[14]

Without any amendment to Oregon's statute, health officials now interpret the law as including chronically ill people who forego "administration of life-sustaining treatment".[15] Recent annual reports have listed underlying illnesses including anorexia, arthritis, arteritis and complications from a fall.[16] Those same reports frequently show patients far exceeding[17] six months between approval and ingestion of the lethal drugs, and of course this doesn't reflect how long they might have lived without doing so. Predicting life expectancy, especially many months from death, is imprecise: a 2017 UCL study found that over half (54%) of those predicted to die within a specified time period lived longer than expected.[18] (We have left Q9 blank, both because any answer implies support for the principle, and because even six months would be too unreliable a prognosis.)

[11] legislation.gov.uk/ukpga/Eliz2/9-10/60
[12] legislation.gov.uk/ukpga/1961/60/pdfs/ukpga_19610060_en.pdf
[13] legislation.gov.im/cms/images/LEGISLATION/PRINCIPAL/1981/1981-0020/CriminalLawAct1981_4.pdf
[14] telegraph.co.uk/comment/10717795/It-sends-a-shiver-down-my-spine.html
[15] carenotkilling.org.uk/articles/six-months-redefined/
[16] Oregon Death with Dignity Act Data Summary 2021, Footnote 3, Page 14.
oregon.gov/oha/PH/PROVIDERPARTNERRESOURCES/EVALUATIONRESEARCH/DEATHWITHDIGNITYACT/Documents/year24.pdf
[17] carenotkilling.org.uk/articles/longer-than-expected/
[18] carenotkilling.org.uk/articles/longer-than-expected/

It is important to note examples of compromises in the framing of assisted suicide legislation being accepted in the short term, and later pushed back against. One year after New Zealand's E&AS law came into effect, the politician who championed its passage, David Seymour, called for one of its defining "safeguards" – a six-month prognosis being required – to be excised[19].

If the Isle of Man breaks step with the rest of the British Isles, even with a minimum residency time requirement, additional dependent patients would likely be attracted to the island wanting the option of assisted suicide in the future, in which case there would be additional social and health costs and workload. While legislators must guard against "suicide tourism" and suicide migration – which is why we have answered "yes" to Q13 – it should be noted that just last year, the same campaign group which co-wrote Oregon's assisted suicide law forced the state, through the courts, to abandon its residency requirement[20], and is now engaged in similar action against Vermont[21].

Canada's law is not yet seven years old, and specialists[22] and parliamentarians there are considering expansion to "mature minors" – having already extended from terminal illnesses to chronic illnesses, and with a further extension to mental illnesses in 2023 only "temporarily" paused in December. Belgium extended its law to children in 2014 by primary legislation, but politicians in the Netherlands – where the current laws already apply to children as young as 12 – are considering a similar move by regulation. The Groningen Protocol in the Netherlands, applying to disabled infants, has never been written into law by the Dutch Parliament. Once euthanasia has become accepted medical practice, incremental extension to those who cannot give informed consent can occur without Parliamentary scrutiny. (We have left Q12 blank because while we oppose inclusion of minors in E&AS legislation, the wording of the question means that "yes" could be taken to indicate support for adult assisted suicide.)

While we do not support providing assisted suicide in response to *any* diagnosis, we have responded "no" to Q10 to emphasise the point that references to "unbearable suffering" are entirely subjective: how can doctors be expected to judge whether the suffering is at a degree to qualify for an assisted suicide? The Netherlands' law uses similar language, requiring that "there was no reasonable alternative solution for the situation in which he [the applicant] found himself."[23] This broad criterion has not only seen the numbers of deaths rise year on year, but has also seen the rate of increase accelerate (as explored further later in this submission.) Belgian law also uses the concept of 'unbearable' suffering. The number of deaths by euthanasia has risen over time in Belgium from just 24 in 2004 to 2,699 in 2021. The Belgian Federal Control Committee itself has stated: "the unbearable nature of the suffering is largely subjective and depends on the patient's personality, ideas and values."[24]

Baroness Campbell is right: the only clear, defensible, non-arbitrary line is to maintain the current law.

[19] nzherald.co.nz/nz/euthanasia-laws-too-strict-and-should-be-relaxed-act-leader-david-seymour-says/AEC6XMXQRJG35CAAZ42KDU7Y5M/
[20] npr.org/2022/03/30/1089647368/oregon-physician-assisted-death-state-residents
[21] cbsnews.com/news/woman-sues-over-residency-requirement-for-assisted-suicide-vermont/
[22] carenotkilling.org.uk/articles/canada-plans-for-child-euthanasia/
[23] wetten.overheid.nl/BWBR0012410/2021-10-01/0
[24] Federal Control Committee, First Report, 2004, p.16

Conscience (Q16)

The World Medical Association is clear that doctors should not be required to participate in E&AS deaths and *"nor should any physician be obliged to make referral decisions to this end"*.[25] All proposals brought forward pay lip service to rights of conscience, but demands are invariably placed upon healthcare professionals (including doctors, nurses and pharmacists.)

Belgium passed a new law in 2020, prohibiting bans on euthanasia in institutional care settings and forcing doctors with conscientious objections to make "effective referrals" (to doctors willing to process E&AS requests).[26] Canada also requires effective referrals from objecting physicians, with judges there endorsing the assertions of Dying with Dignity Canada that:

> "If a doctor is unwilling to take the less onerous step of structuring their practice in a manner that ensures that their personal views do not stand in the way of [facilitating E&AS] … then the more onerous requirement of a transfer into a new specialty is a reasonable burden for that doctor to bear."[27]

What importance do MHKs place on conscience rights? What of the rights of patients in units not permitted to exclude assisted suicide? Do MHKs agree that it is better for doctors to leave their specialties, or medicine itself, than impede an assisted suicide? The Isle of Man has the same health and social care recruitment problems as England, with the additional difficulty of being an island which adds issues around relocation, especially when two in a household are both working.

It is worth remembering that BMA[28], RCP[29] and APM[30] surveys have all shown that doctors working in specialties closest to dying people – palliative medicine, geriatric medicine, respiratory medicine and general practice – are most opposed. A 2019 joint statement issued by the Canadian Hospice Palliative Care Association and Canadian Society of Palliative Care Physicians stated that:

> "MAiD [Medical Assistance in Dying – E&AS] is not part of hospice palliative care; it is not an "extension" of palliative care nor is it one of the tools "in the palliative care basket"… Hospice palliative care and MAiD substantially differ in multiple areas including in philosophy, intention and approach."[31]

Would funding be in question for homes and hospices which refused permission?[32] At least one hospice in Canada has lost funding owing to its unwillingness to provide euthanasia deaths on its premises, and a New Zealand judge has ruled that health authorities would be within their rights to consider willingness to permit E&AS when reviewing funding for hospices.[33]

Isle of Man Hospice Chief Executive Anne Mills and Lead Clinician Dr Benjamin Harris have said that any change would also place medical and nursing staff in an "invidious position":

[25] wma.net/policy-tags/euthanasia/#:~:text=The%20WMA%20reiterates%20its%20strong,euthanasia%20and%20physician%2Dassisted%20suicide.
[26] ieb-eib.org/en/news/end-of-life/euthanasia-and-assisted-suicide/breaking-news-the-belgian-constitutional-court-rejects-the-appeal-relating-to-the-2020-law-on-euthanasia-2086.html?backto=search
[27] canlii.org/en/on/onca/doc/2019/2019onca393/2019onca393.html
[28] carenotkilling.org.uk/articles/bma-assisted-dying-poll-takeaways/
[29] carenotkilling.org.uk/articles/rcp-consultation-key-takeaways/
[30] apmonline.org/wp-content/uploads/2015/05/APM-survey-on-Assisted-Suicide-website.pdf
[31] cspcp.ca/wp-content/uploads/2019/11/CHPCA-and-CSPCP-Statement-on-HPC-and-MAiD-Final.pdf
[32] scoop.co.nz/stories/AK2006/S00673/euthanasia-referendum-threat-to-hospice-movement.htm
[33] toronto.citynews.ca/2020/02/25/b-c-hospice-loses-funding-after-refusing-to-provide-assistance-in-dying/

> "In providing care at the end of life we seek neither to hasten nor delay the time of death. This being the case we would regard it inappropriate for Hospice staff to take part in any assisted dying process, even if that were legalised on the Isle of Man."[34]

We urge MHKs to heed the warnings of Manx Duty of Care, a group of more than 50 Isle of Man-based health and social care workers.[35]

Process (Qs 11, 15 & 17-27)

Regarding Q11, the definition of the term "unable" (to take oral medication) could clearly be reinterpreted: physically incapable, physically difficult, emotionally difficult, nervous… If the principle of physician administration is accepted, it would be hard to justify denying the option to anyone deemed eligible, which would place a still greater demand on doctors. Canada's MAiD regime offers both E&AS, with 99% of participants opting for euthanasia. We are also aware of "combination" deaths in the Netherlands: euthanasia where assisted suicide has failed, a reminder of the complications which can arise.[36]

We note known difficulties with establishing mental capacity for decisions far less momentous than assisted suicide. Given question marks over how "independent" doctors can be from each other in reality, and also concerns over doctor-shopping, we have left Q15 blank. In Oregon, doctor-shopping has become commonplace. Oregon Health Authority reports on assisted suicide show patients often being approved by doctors they have only known for a few days.[37] This impairs the ability to understand the patient and their illness, and to detect coercion, which can be subtle. Effectively detecting coercion is not something for which most doctors are trained, and the requirement to do so would increase pressure on service providers.

A survey in England and Wales conducted by the charity SafeLives found that on average, victims at high risk of serious harm or murder live with domestic abuse for 2-3 years before getting help. 85% of victims sought help five times on average from professionals in the year before they got effective help to stop the abuse.[38] How would subtle coercion be effectively detected, particularly in a shorter timeframe when the participating healthcare professionals may not know the patient well?

Regarding Q17, we would argue that *all* applicants should undergo such an assessment. Past-President of the Royal College of Psychiatrists Baroness Hollins has written[39] that assessing mental capacity:

> "isn't like checking the oil or water level in a car… [or] the sort of thing that can be done in a single consultation, especially if the decision in question – as it is in this case – is one with life-or-death consequences."
>
> "Researchers have found that some patients who have ended their lives under the terms of Oregon's assisted suicide law had been suffering from clinical depression. Depression impairs decision-making capacity, it is common in elderly people and it is treatable. But in

[34] manxradio.com/news/isle-of-man-news/mhk-supports-public-conversation-over-assisted-dying/
[35] iomtoday.co.im/news/fifty-medics-get-together-to-say-we-dont-want-euthanasia-587309
[36] www.carenotkilling.org.uk/articles/assisted-dying-inhumane/
[37] carenotkilling.org.uk/articles/oregon-2021-anorexia-hernias-feeling-a-burden/
[38] SafeLives (2015), Insights Idva National Dataset 2013-14. Bristol: SafeLives. Available at: safelives.org.uk/policy-evidence/about-domestic-abuse#top%2010
[39] livinganddyingwell.org.uk/assisted-dying-bill-can-you-really-tell-if-someones-of-sound-and-settled-mind-for-suicide/

> some cases in Oregon it has not been diagnosed by the doctor who assessed the patient's capacity and prescribed lethal drugs. Oregon's law requires referral for psychiatric examination in cases of doubt but in some cases that has not happened."

There is merit, regarding Q18, in considering whether doctors should be required to see evidence of patients having *experienced* the holistic care that comes with hospice treatment, rather than simply having been "fully informed."

The question does prompt another question, which featured in the recent consultation in Jersey and with which MHKs must grapple: could healthcare professionals raise the "option" of assisted suicide with patients, including those who had not raised it themselves?

Doctors are expected to inform patients of all available options, even if they have a conscientious objection to taking part, as per the GMC's guidance[40]. A patient who expresses a wish to die needs a compassionate response and space to explore what that really means, since often it is not a genuine wish to die but an expression of another form of distress. However, a doctor who raises the issue of assisted suicide, may be perceived to be suggesting or recommending that as a course of action. Combined with the inevitable pressures of the cost of treatment and lack of resources, this may well lead to people seeking death by assisted suicide owing to external pressures.

Canada's law states that no healthcare professional commits an offence "if they provide information to a person on the lawful provision of medical assistance in dying," paving the way for a 2019 document issued by the Canadian Association of MAID Assessors and Providers which asserts that "physicians and nurse practitioners… involved in care planning and consent processes have a professional obligation to initiate a discussion about MAiD if a patient might be eligible for MAiD."[41]

If assisted suicide became legal and a mandatory part of healthcare discussions, no person with an eligible illness would be able to avoid considering the "choice" on offer and may well feel a public duty to die in order to avoid being a burden on family, friends and care services. This is increasingly the case in Oregon with over 50% of those having an assisted suicide now regularly citing this reason for seeking death.[42]

How would financial considerations factor into the reality of legalised assisted suicide?

Prior to the expansion of Canada's MAiD law beyond terminal illnesses, the Parliamentary Budget Office there produced a report which estimated that under the then-law, 6,465 people would die by MAiD in 2021 - 2.2% of all deaths - with net healthcare savings of $86.9m. The PBO expected amending the law to add 1,164 deaths to that figure in the first year alone, leading to increased healthcare savings in 2021 of $149m - almost £87m.

Earlier that same year (2020), the journal *Clinical Ethics* published a controversial paper in which ethicist David Shaw and health economist Alec Morton argued, per *The Times*, "that granting terminally-ill patients help to die would save money and potentially release organs for transplant."[43]

[40] gmc-uk.org/ethical-guidance/ethical-guidance-for-doctors/good-medical-practice/domain-3---communication-partnership-and-teamwork#paragraph-31
[41] nationalpost.com/news/canada/canada-maid-medical-aid-in-dying-consent-doctors
[42] More than 54% in 2021 oregon.gov/oha/PH/PROVIDERPARTNERRESOURCES/EVALUATIONRESEARCH/DEATHWITHDIGNITYACT/Pages/ar-index.aspx
[43] carenotkilling.org.uk/articles/widening-canadas-euthanasia-law-set-to-save-149m/

Without wishing to indicate reassurance by anything less formal, we have left Q19 (and Q20) blank so as not to endorse legalisation of assisted suicide.

Regarding Q21, we have answered "no" to emphasise that such waiting times are vulnerable to later relaxation of any law: Oregon's Death with Dignity Act was amended in 2019 to allow the waiving of a 15-day waiting period.[44]

Regarding Q22, allowing lethal unregulated doses of drugs to circulate in the community unmonitored and without being certain of the destination would be dangerous; questions arise over conscience rights for pharmacists. Regarding Q23 & Q24, we note that the presence of lethal unregulated doses of drugs in people's homes is dangerous.

We have left Q25, concerning presence at assisted suicide deaths, blank, conscious of the moral, ethical and practical burden this would place on healthcare professionals. MHKs must address the growing body of research on complications in E&AS. Research published in the journal *Anaesthesia* suggested that a relatively high incidence of vomiting, prolongation of death and reawakening from coma could render such deaths "inhumane,"[45] while Dr Joel Zivot, writing in the *Spectator*, has observed that often, "paralytic drugs are used [in euthanasia]. These drugs, given in high enough doses, mean that a patient cannot move a muscle, cannot express any outward or visible sign of pain. But that doesn't mean that he or she is free from suffering."[46]

We have answered "yes" to Q26, and take this opportunity to argue that advocates must not be allowed to leave the details of review procedures and the intended contents of annual reports to later regulations: the plans must be open to scrutiny before *any* further legislative steps are taken.

Where E&AS are legalised, the numbers of deaths tend to rise annually. E&AS accounted for at least 4.5% of Dutch deaths in 2021 (up from 4.1% in 2020[47]), and at least 3.3% of Canadian deaths in 2021 (up from 2.5% in 2020 and 2.0% in 2019[48]). Such laws are necessarily founded on arbitrary limits, which are breached with relative impunity, reinterpreted or expanded.

In 2013 in Belgium, 1.7% of all deaths were of physician-administered euthanasia without the explicit consent of the patient, representing over 1,000 deaths that year.[49] Similarly in 2010 in one survey in Belgium, 50% of nurses involved in administering euthanasia admitted to cases where no consent was obtained.[50]

Regulation of E&AS relies on consistent and independent reporting in order to be meaningful. The European Court of Human Rights' ruling[51] in the case of Tom Mortier illustrates the difficulties of developing a robust system of post-mortem review. Tom's mother was Godelieva de Troyer, a Belgian woman with long-term depression who was euthanised without the support of her psychiatrist by the co-chair of the euthanasia review body, to whose pro-euthanasia organisation she had donated money, with her son only finding out the day after she had died.[52]

[44] oregonlive.com/politics/2019/07/new-law-shortens-death-with-dignity-waiting-period-for-some-patients.html
[45] carenotkilling.org.uk/articles/assisted-dying-inhumane/
[46] spectator.co.uk/article/last-rights-assisted-suicide-is-neither-painless-nor-dignified/
[47] euthanasiecommissie.nl/de-toetsingscommissies/uitspraken/jaarverslagen/2021/maart/31/jaarverslag-2021
[48] canada.ca/en/health-canada/services/medical-assistance-dying/annual-report-2021.html#a3.2
[49] lozierinstitute.org/study-more-than-1000-deaths-hastened-without-patients-explicit-request-in-belgium/
[50] dailymail.co.uk/news/article-1285423/Half-Belgiums-euthanasia-nurses-admit-killing-consent.html
[51] adfinternational.org/tom-mortier-ruling/
[52] adfinternational.org/tom-mortier/

Reporting deficiencies are widespread. The Disability Rights Education & Defense Fund tells us that:

> "Oregon's annual reports on their assisted suicide statistics, highly praised by proponents as informative, actually tell us very little. Available data is quite minimal and there is no real oversight, investigation of abuse, enforcement, penalties for non-compliance, nor monitoring."[53]

Worthington, Regnard, Sleeman and Finlay published "the first study to compare the reporting on assisted suicide and euthanasia across all jurisdictions where it is legal" in *BMJ Supportive & Palliative Care* in December 2022. They found that:

> "All of the information included within the reports is self-reported retrospectively by the prescribing clinician. Analyses from Belgium and the Netherlands, where review processes are established, have shown that 48% of assisted deaths in Belgium and one in five of such deaths in the Netherlands are not reported, and in some cases legal requirements are not followed."[54]

The *official* figures cited a few paragraphs ago – E&AS as a proportion of all deaths – should be read with this under-reporting in mind.

Given (Q27) the openness of proponents (as demonstrated by Qs 10 & 11) to E&AS for broader categories of people, it is important to remember the significance of dementia as a terminal illness. The Netherlands permits euthanasia for patients on the basis of mental illness and dementia (115 and 215 deaths respectively in 2021[55]). A Dutch woman with dementia was restrained by her family to allow a doctor to euthanise her in line with an advance directive.[56] When the doctor and the family sought to conduct the euthanasia procedure, the patient resisted and said no three times. The doctor put a sedative in the patient's coffee and she was held down by her son-in-law whilst the doctor administered the lethal drugs to end her life. At a subsequent trial, the doctor was acquitted and later the Supreme Court of the Netherlands confirmed that doctors acting in this way is compatible with the Dutch euthanasia law. The courts ruled that the doctor "did not have to verify the current desire to die."[57]

[53] dredf.org/public-policy/assisted-suicide/oregon-so-called-safeguards-and-minimal-data/

[54] Worthington A, Regnard C, Sleeman KE, et alComparison of official reporting on assisted suicide and euthanasia across jurisdictionsBMJ Supportive & Palliative Care Published Online First: 30 December 2022. doi: 10.1136/spcare-2022-003944

[55] euthanasiecommissie.nl/de-toetsingscommissies/uitspraken/jaarverslagen/2021/maart/31/jaarverslag-2021

[56] bbc.co.uk/news/world-europe-52367644

[57] apnews.com/article/europe-health-courts-dementia-euthanasia-1ed45f0819e788708da51d161b48e9f8
apnews.com/article/a041563e55204279bfb8e335a19c2802