

Assisted Dying for Terminally Ill Adults (Scotland) Bill

Liam McArthur MSP

A proposal for a Bill to enable competent adults who are terminally ill to be provided at their request with assistance to end their life.

Consultation by Liam McArthur MSP, Scottish Liberal Democrat Member for Orkney Islands

Response on behalf of

Care Not Killing (CNK Alliance Ltd)

and

Our Duty Of Care

December 2021

About You

1. Are you responding as:

on behalf of an organisation? – in which case go to Q2B

2B. Please select the category which best describes your organisation:

Third sector (charitable, campaigning, social enterprise, voluntary, nonprofit)

Optional: You may wish to explain briefly what the organisation does, its experience and expertise in the subject-matter of the consultation, and how the view expressed in the response was arrived at (e.g. whether it is the view of particular office-holders or has been approved by the membership as a whole).

Care Not Killing (CNK) is a UK-based alliance of individuals and organisations which brings together disability and human rights groups, healthcare providers, and faith-based bodies, with the aims of:

- promoting more and better palliative care;
- ensuring that existing laws against euthanasia and assisted suicide are not weakened or repealed;
- influencing 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. We are a campaign that is financed and administered by the Care Not Killing alliance. It is supported by a wide range of healthcare professionals – over 1,700 across the UK including 230 who recently signed an open letter to Health Secretary Humza Yousaf – and has campaigned during the membership polls run by the Royal College of Physicians, Royal College of General Practitioners and British Medical Association to maintain medical opposition to assisted suicide. The campaign is administered by Dr Gillian Wright, a former palliative care doctor based in Scotland, and Dr David Randall, a specialty registrar in renal medicine working in London.”

This is a joint submission, agreed by CNK CEO Dr Gordon Macdonald and ODOC Director Dr Gillian Wright in line with longstanding policy.

3. Please choose one of the following:

I am content for this response to be published and attributed to me or my organisation

4. Please provide your name or the name of your organisation. (Note: The name will not be published if you have asked for the response to be anonymous or “not for publication”.)

Name: Care Not Killing (CNK Alliance Ltd) and Our Duty of Care

Contact details: info@carenotkilling.org.uk

5. Data protection declaration

I confirm that I have read and understood the Privacy Notice which explains how my personal data will be used.

Your views on the proposal

1. Which of the following best expresses your view of the proposed Bill?

Fully opposed

Please explain the reasons for your response.

Care Not Killing was established to oppose the legalisation of assisted suicide and euthanasia, and to promote improvements in provision of and access to palliative care and broader community support as the proper responses to end of life concerns and suffering. We have engaged with evidence from across the world over the last 16 years and remain firm in our contention that assisted suicide laws are:

- Uncontrollable: once the principle is accepted into law, it is subject to abuse and extension as arbitrary lines are redrawn as seen in Oregon¹, Canada, the Netherlands, Belgium and beyond.
- Unethical: legalisation would make assisted suicide a treatment option to be offered alongside others, forcing the choice upon all eligible patients and making it a budgetary consideration when the great expense of end-of-life care is under review. To say in law that some suicides are to be prevented, and others assisted, necessarily devalues people's lives. Healthcare professionals are placed in the invidious position of having to respond to requests from their patients for assisted suicide or euthanasia which go against their code of medical ethics.
- Unnecessary: repeated studies have found that end of life suffering is often rooted in a lack of access to palliative care, including access to specialist palliative care, and also to constraints on living with dignity with proper financial and community support.

We find that the proposal before MSPs is deficient even in comparison with dangerous laws already in place elsewhere, as we shall go on to explain.

2. Do you think legislation is required, or are there are other ways in which the Bill's aims could be achieved more effectively? Please explain the reasons for your response.

No.

Specifically regarding the bill's aims, there is an obvious and ominous problem:

"The aim of the proposal is to enable mentally competent adults who are terminally ill to be provided with assistance to end their life at their request." (p7)

While the consultation goes on to consider different aspects of end of life need in Scotland, the simple fact is that meeting end of life suffering isn't actually mentioned in the stated aim; decriminalising and facilitating assisted suicide is an end in itself, the fulfilment of an ideological aim (autonomy). The Bill's aims should be to meet human need, and such a lethal response should be unthinkable while we are yet to ensure equitable access to fully-funded palliative care and adequate financial support for dignity in living for those with terminal and chronic illnesses, and disabilities.

¹ carenotkilling.org.uk/articles/six-months-redefined/

3. Which of the following best expresses your view of the proposed process for assisted dying as set out at section 3.1 (Step 1 - Declaration, Step 2 – Reflection period, Step 3 - Prescribing/delivering)?

Fully opposed

Please explain the reasons for your response, including if you think there should be any additional measures, or if any of the existing proposed measures should be removed. In particular, we are keen to hear views on Step 2 – Reflection period, and the length of time that is most appropriate.

Regarding medical approval of assisted suicide, we are told:

The declaration must be signed by a registered medical doctor from whom the person has requested assistance to end their life (the attending doctor) and another registered medical doctor (independent doctor). Before signing the person's declaration, the attending and independent doctor must separately examine the person and the person's medical records and, each acting independently of the other, be satisfied that the person is terminally ill, has the capacity to make such a decision, and has reached a clear and settled intention on an informed basis, without coercion or duress. (p19)

“Independent” is the word we are meant to be reassured by: early on in the document, we are reassured that “two doctors *independently* confirm the person is terminally ill.” (p7) Yet the intention to develop “a register of HCPs and staff whose personal ethics do permit participation” (p22) is far more instructive: once a patient has been approved for assisted suicide by one doctor, it is to be assumed a principal purpose of such a register will be to refer requesting patients for second signatures, but in reality, such a register would represent those healthcare professionals so inclined to see assisted suicide as a good in itself that they are predisposed to support, rather than scrutinise, such decisions.

Doctor-shopping is a real and proven phenomenon in jurisdictions like Oregon, where in 2020, “a total of 142 physicians wrote 370 prescriptions... (1-31 prescriptions per physician).” The clarification that “79% of physicians wrote one or two prescriptions” really only draws attention to the fact that 21% wrote more, with at least one prescribing lethal cocktails every 11 or 12 days. The gravity of this fact is reinforced by the report noting that some assisted suicides were approved by doctors who had known the patients in question for less than a week.² We have drawn to public attention the consultation leaving open the possibility that such appointments need not even be in person but could take place over video-calls³, as has been seen in the United States during the pandemic,⁴ meaning that patients could be approved for assisted suicide by physicians who have no prior knowledge of them, who have never even met them in person, and who are predisposed to assent.

As “palliative medicine doctors and academics with decades of experience caring for terminally ill people” have recently warned, “evidence from Oregon shows how assessment of capacity for assisted suicide is influenced by the individual values of assessing clinicians, something that is almost impossible to mitigate against.”⁵

Moving forward to the role of healthcare professionals at the actual point of death, we are told that “the person must administer the life-ending medication themselves” (p7) and that “it would continue to be a criminal offence to end someone’s life directly” (p8). Deeper within the consultation, it is noted that “the HCP present may then prepare the medicine for self-administration by that person” (p20) which rather begs the question: where is the line drawn between administration and self-administration? It is assumed that preparing the concoction doesn’t cross the line, but does handing it to a patient? Would guiding an unsteady hand to lips be acceptable? Or is the definitive act the

² oregon.gov/oha/PH/PROVIDERPARTNERRESOURCES/EVALUATIONRESEARCH/DEATHWITHDIGNITYACT/Documents/year23.pdf

³ thetimes.co.uk/article/proposed-law-change-to-allow-assisted-suicide-bookings-over-zoom-w5r2lq9s3

⁴ theconversation.com/dying-virtually-pandemic-drives-medically-assisted-deaths-online-139093

⁵ thetimes.co.uk/article/times-letters-reasons-for-modernising-the-honours-system-k5nwxlhjg

swallowing, in which case can the attending HCP go so far as help the drugs onto the tongue? Physical contact might seem the dividing line, but then what if the prescription were to be delivered intravenously – with the HCP fitting a cannula – with the intention being that the patient releases the substance, as was considered in the context of Tony Nicklinson’s court challenges?⁶ The dividing line between assisted suicide and euthanasia is to a great extent a fiction, of course: as eminent palliative care physician Prof Rob George has said, for a doctor, the decision to prescribe lethal medication is the same as the decision to administer a lethal substance.⁷

4. Which of the following best expresses your views of the safeguards proposed in section 1.1 of the consultation document?

Fully opposed

Please explain the reasons for your response.

The defining “safeguard” of this proposal, as with similar, recent proposals in neighbouring jurisdictions, is that it is limited to terminally ill people, and indeed Mr McArthur, in his foreword, goes so far as to reject references to “assisted suicide” on that basis:

The use of ‘suicide’ in this context is not appropriate, given that the person will only be able to request an assisted death if they have a terminal illness that will end their life i.e. the choice to live has already been taken away, the choice of an assisted death allows the inevitable dying process to be less traumatic. (p3)

However, unlike other Oregon-style proposals in, for example, Westminster, the definition of “terminally ill” does not include a particular life expectancy:

In Scotland, a person is terminally ill if a registered medical practitioner has diagnosed them as having a progressive disease, which can reasonably be expected to cause their death. Terminal illness is defined, for the purposes of providing social security, as that suffered by those who are deemed by doctors as ‘unable to recover’, regardless of the time they have left to live. This is Scottish Government Policy, supported by members of the Scottish Parliament. It was thoroughly considered and decided upon during the passing of the Social Security (Scotland) Act 2018. Under the previous system, a claimant was not deemed to be suffering from a terminal illness unless medics considered that they had six months or less to live. (p21)

Scotland can rightly be proud of ensuring that seriously ill patients should not face unnecessary barriers to support to live, and indeed where we lead, others rightly follow with a campaign at Westminster to similarly remove the six-month requirement for benefits access. It is however absurd to suggest that “people would not qualify under this proposal’s criteria by having a disability alone. The choice would only be available if they also have a terminal illness” (p23).

Baroness Campbell of Surbiton, who lives with spinal muscular dystrophy and was expected to die before reaching the age of one, addressed the House of Lords in 2015, highlighted comparable deficiencies in Lord Falconer’s failed Assisted Dying Bill (which included a six-month prognosis threshold):

Proponents of the Bill claim that “disabled” and “terminally ill” are distinct from one another. We are told that disabled people can be assured that the Bill is not intended to apply to them... I am fearful of the Bill not least because terminal illness is defined as an

⁶ independent.co.uk/life-style/gadgets-and-tech/news/suicide-machine-assisted-dying-euthanasia-debate-uk-clinic-sarco-nitschke-a8307741.html

⁷ faithdebates.org.uk/wp-content/uploads/2013/09/1367921574_WFD2013_Assisted_Dying-George.mp3 3m08s

“inevitably progressive condition which cannot be reversed by treatment”.

That definition could equally apply to many disabilities, my own included... I therefore looked at who the Bill might encompass. The brain, eyes, lungs, kidneys, pancreas, joints and nerves can all be subject to “inevitably progressive” conditions deteriorating at widely differing rates. Various forms of cancer, heart disease and neurological conditions can fit the criteria for “inevitably progressive” at some stages. Children and young people are born and are surviving with a variety of life-limiting conditions for which the prognosis is very uncertain. Overall, significant numbers of children and adults fall within categories to which the definition,

“an inevitably progressive condition which cannot be reversed by treatment”,

is applicable. I found that it is only the fact that most are not,

“reasonably expected to die within six months”,

that keeps them outside the scope of the Bill.⁸

Let us be clear: the definition of “terminal illness” as applied to social security access serves to relieve an administrative burden from ill people, but Mr McArthur’s suggestion that “the choice to live has already been taken away” from those encompassed by the bill, when they could in fact live for years or decades, is simply wrong.

Aspects of the proposal indicate a degree of wishful thinking: that doctors need not (as already noted) know or even meet in person patients applying for assisted suicide compounds the already variable ability of doctors to detect “pressure or coercion” (p7).

In seeking to identify situations without “safeguards”, the proposal perpetuates misunderstandings:

Under the current law, decisions that doctors can take that may hasten a person’s death, such as withdrawing treatment or double effect, involve far fewer safeguards and less oversight than would be present under an assisted dying law.

Double effect is often spoken of as a common occurrence easily slipped into, but in reality, the space between a therapeutic and lethal doses of morphine (for example) is substantial.⁹ When symptoms merit a higher dose, it is often the case that the patient in question will by then have developed a higher tolerance. It is unhelpful to speak as if double effect is easily achieved. On the other hand, it is quite simply incorrect to speak of withdrawing treatment on the same level as assisting suicide: ingesting lethal drugs is an intervention which causes death, whereas withdrawing life-prolonging treatment simply ends an intervention which prevented a natural death.

It is interesting that the consultation document should include reference to such practices: recent polling in the UK¹⁰ and New Zealand¹¹ has revealed significant public confusion¹¹ as to whether “assisted dying” would include ending life-prolonging treatments. Mr McArthur and allied campaigners’ insistence on using the euphemism “assisted dying” rather than the more accurate “assisted suicide” only adds to public confusion.

The consultation also makes unsustainable leaps of logic:

Where some doctors are currently acting illegally to directly end a person’s life at their request (voluntary euthanasia), there are no safeguards in place at all. The barrier that the current law creates does not stop people

⁸ [hansard.parliament.uk/Lords/2015-01-16/debates/15011659001145/AssistedDyingBill\(HL\)](https://hansard.parliament.uk/Lords/2015-01-16/debates/15011659001145/AssistedDyingBill(HL))

⁹ bma.org.uk/media/1424/bma-guidance-on-responding-to-patient-requests-for-assisted-dying-for-doctors.pdf

¹⁰ dyingwell.co.uk/wp-content/uploads/2021/09/Survation-Assisted-Dying-Survey-July-2021-Summary-3.pdf

¹¹ carenotkilling.org.uk/articles/nz-vote-based-on-widespread-confusion/

taking action to control the end of their lives but instead drives the practice behind closed doors. This means potentially vulnerable people cannot be and are not being protected. (p17)

The proposal before us seeks to answer law-breaking by simply removing the offence in particular circumstances, but where patients would not (yet) be eligible, those acts would remain “behind closed doors.” That a law is being broken or circumvented cannot in and of itself be a reason for that law to be weakened or suppressed, or else we would have no laws.

5. Which of the following best expresses your view of a body being responsible for reporting and collecting data?

Fully opposed

Please explain the reasons for your response, including whether you think this should be a new or existing body (and if so, which body) and what data you think should be collected.

We confine our remarks to the statement that:

Death certificates are public documents, and in the interests of privacy, the primary cause of death would be noted as the underlying illness from which the person died. It is envisaged that the paperwork and the potential creation of a reporting and oversight body would satisfy public health awareness, research and resource allocation requirements. (p20)

If a cancer patient with a terminal prognosis was killed in a road traffic accident, their death certificate would list injuries resulting from the accident as being the cause. If the same patient, at the same moment on the same day, ingested lethal drugs causing their heart to stop, this proposal requires that their cause of death be registered as cancer. The use of the word “primary” suggests that the certificate will at least mention “assisted dying” – making the certificate merely misleading – but the strong emphasis on “privacy” suggests it may not be mentioned at all – meaning registrars would be required to lie on public records as a matter of course. If proponents believe “assisted dying” to be an ethical practice, why does it need to be hidden? “Assisted dying” is a distasteful enough euphemism, but the tendency to obscure the facts of the matter has reached the level of debasing trust in public records. This cannot – cannot – serve transparency or justice.

6. Please provide comment on how a conscientious objection (or other avenue to ensure voluntary participation by healthcare professionals) might best be facilitated.

As is so often the case, “however” marks the break between what should be heard to be said, and what is actually meant and planned:

*It is important that doctors and other healthcare professionals are able to conscientiously object (CO) to supporting their patients through an assisted dying request. It is recognised, **however**, that if the Bill becomes law it would be the patient’s legal right to request assistance, and a referral to another consenting doctor should be made if the initial doctor declined to assist the patient because of their personal beliefs... The policy intent is that no person will be obliged to participate in the assisted dying process. (p21-22)*

As is spelled out in the consultation document, a register of those content to approve assisted suicide requests is envisaged, and while access is yet to be specified, it is to be assumed that making referrals as mentioned above would be a key purpose. It is a nonsense to suggest that a doctor has not been required to “participate” in the process of

causing a patient's death if statute demands that they in every instance refer the requesting patient to a doctor who is predisposed to say "yes".

Effective referrals already exist in Canada, as settled by the Ontario Court of Appeal in *Christian Medical and Dental Society of Canada v. College of Physicians and Surgeons of Ontario* (2019)¹². The Court's ruling makes extensive reference to witness testimony outlining how objecting

physicians may be able to change or narrow their "scope of practice"... He points to the following areas as areas of medicine in which physicians are unlikely to encounter requests for referrals for MAiD... concerns, and which may not require specialty retraining or certification: sleep medicine, hair restoration, sport and exercise medicine, hernia repair, skin disorders for general practitioners, obesity medicine, aviation examinations, travel medicine, and practice as a medical officer of health. He also points to other roles in which a physician would be shielded from patient requests for referrals, such as administrative medicine or surgical assistance.

Ultimately, that Court recorded,

As the Divisional Court observed, the appellants have no common law, proprietary or constitutional right to practice medicine. As members of a regulated and publicly-funded profession, they are subject to requirements that focus on the public interest, rather than their interests. In fact, the fiduciary nature of the physician-patient relationship requires physicians to act at all times in their patients' best interests, and to avoid conflicts between their own interests and their patients' interests

(The assumption being that a patient's best interests are served by valuing autonomy above life and health.)

The consultation document is littered with references to "clarity" and "transparency". The medical community in Scotland deserve these too, and the proposal's proponents should state clearly that planned conscience protections would minimise but still require a degree of participation in the process where a request is made. Would they consider it in the broader interests of Scots' health for healthcare professionals to feel unable to continue in a particular specialty or even in practice at all, as hinted at in the Ontario ruling? The legalisation of assisted suicide is likely to lead to some people choosing to exit medicine (or other healthcare professions), possibly by opting to retire. It will add to the recruitment crisis in the NHS and lead to reductions in service to the general public which potentially puts peoples' lives at risk through undiagnosed or late-diagnosed conditions.

The consultation document does not address the right of end-of-life care institutions to exclude euthanasia. On 16 June 2020, a New Zealand High Court considering a case brought by Hospice NZ supported the right of hospices to prohibit euthanasia, but the judge stated in his decision that there was however nothing to prevent the government authority from withholding health care funding if a hospice refused to allow euthanasia.¹³

The Attorney General submitted to the court... if a DHB determined the most efficient way to fund assisted dying services in its area was to fund a provider who is willing to provide both palliative care and assisted dying services, it must be entitled to do so. Such a decision would not be to discriminate against those holding a conscientious objection. Rather, it would be one of effective allocation of funding to service providers in accordance with the statutory requirement on a DHB that it "seek the optimum arrangement for the most effective and efficient delivery of health services in order to meet local, regional and national needs".

If Scottish hospices unwilling to accommodate assisted suicide lost statutory funding as a result, would the framers of this consultation consider that acceptable collateral damage? This is not a hypothetical question: even as that case was heard and ruled on, a long-running confrontation in Canada saw British Columbia health authorities withdraw

¹² ontariocourts.ca/decisions/2019/2019ONCA0393.pdf

¹³ scoop.co.nz/stories/AK2006/S00673/euthanasia-referendum-threat-to-hospice-movement.htm

essential funding from a hospice operator (Delta Hospice Society) for refusing to offer patients “medical assistance in dying”.¹⁴

(On a point of accuracy regarding medical opinion, we note a footnote on p13: “The Royal College of General Practitioners has maintained its opposition to assisted dying, despite a majority of GPs voting to support a change in the law or adopt a neutral stance.” This is a ludicrous statement: the authors could as easily have noted that a *larger* majority – 58% – voted to reject support for a change in the law, and since moving to neutrality was supported by just 11%, the RCGP pursued the only logical course in aligning its position with the most favoured position, opposition.¹⁵)

Financial implications

7. Taking into account all those likely to be affected (including public sector bodies, businesses and individuals etc), is the proposed Bill likely to lead to:

A significant reduction in costs.

Please indicate where you would expect the impact identified to fall (including public sector bodies, businesses and individuals etc). You may also wish to suggest ways in which the aims of the Bill could be delivered more cost-effectively.

2015 polling¹⁶ commissioned ahead of debate on a House of Commons bill found that some 86% felt there was a risk that NHS managers or politicians would prioritise “assisted dying” over end of life care to save money if the law changed. Barely a week goes by without political confrontations over the level and sufficiency of funding for the health service, with postcode lotteries depriving patients in certain locations (or of certain ages of prognoses) or life-changing care.

As Canadian lawmakers prepared to legislate for a court-ordered expansion of its euthanasia and assisted suicide law (beyond those whose deaths are reasonably foreseeable) in 2020, they were presented with a report from the Canadian Parliamentary Budget Office (PBO), laying out estimates of expected numbers of Medical Assistance in Dying (MAiD) deaths in 2021, and the likely costs and savings involved.¹⁷ Euthanasia and assisted suicide have only been legal across Canada since 2016, and yet by 2019, the official annual total¹⁸ of state-sponsored deaths had reached 5,631 (accounting for 2% of all deaths in Canada and representing an increase of 26.1% over 2018) in a country with a population little more than half that of the UK's.

When all data sources are considered, the total of number of medically assisted deaths reported in Canada since the enactment of federal legislation is 13,946.

The PBO estimated that under the current law, 6,465 people would die by MAiD in 2021 - 2.2% of all deaths - with net healthcare savings of \$86.9m. The PBO expects 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.

¹⁴ catholicregister.org/item/31746-court-deals-blow-to-delta-hospice news.gov.bc.ca/releases/2020HLTH0047-000328

¹⁵ rcgp.org.uk/about-us/news/2020/february/royal-college-of-gps-remains-opposed-to-change-in-the-law-on-assisted-dying.aspx

¹⁶ premierchristian.news/en/news/article/exclusive-as-mps-discuss-assisted-dying-poll-shows-76-think-terminally-ill-would-feel-responsibility-to-die-early

¹⁷ pbo-dpb.gc.ca/web/default/files/Documents/Reports/RP-2021-025-M/RP-2021-025-M_en.pdf

¹⁸ canada.ca/content/dam/hc-sc/documents/services/medical-assistance-dying-annual-report-2019/maid-annual-report-eng.pdf

Such considerations are being made elsewhere. Earlier in 2020, the journal *Clinical Ethics* published¹⁹ a highly controversial paper in which, as *The Times*²⁰ reported:

David Shaw, an ethicist, and Alec Morton, a health economist, argue that granting terminally-ill patients help to die would save money and potentially release organs for transplant.

Dr Shaw, who is based in Glasgow... described the potential savings of allowing assisted dying as “the elephant in the room”. He said: “We are simply arguing that the economic costs of denying assisted dying should not be ignored; they should not be the key driver of any legal change, but it would be irresponsible not to consider them.” The researchers have assessed how much euthanasia could help patients using the same formula which bodies such as Nice deploy to weigh up the expense and benefits of new drugs.

The PBO goes on to acknowledge that:

Our estimates have only taken into consideration the health care costs from the perspective of provincial governments. Therefore, out-of-pocket costs paid by patients or their relatives have not been considered. For example, palliative care is usually free of charge when provided in a hospital or a government funded hospice, but there could be costs billed to patients in nursing homes or wanting to receive palliative care at home.

Canadian reports²¹ indicates that 34% of MAiD participants “perceived [themselves to be a] burden on family, friends or caregivers”, and we consistently see this concern cited to a far greater degree in jurisdictions like Oregon - 53%²² in 2020, when 7.4% also specifically cited the financial implications of continuing treatment.

Legalising and facilitating assisted suicide as a treatment option makes the lethal option the cheapest one, and in so doing cheapens every life deemed eligible. Mr McArthur should acknowledge this point about the danger of cost savings becoming a motivation for people seeking assisted suicides and/or a subtle pressure which becomes applied on healthcare professionals to acquiesce to such requests.²³

Equalities

8. What overall impact is the proposed Bill likely to have on equality, taking account of the following protected characteristics (under the Equality Act 2010): age, disability, gender re-assignment, marriage and civil partnership, pregnancy and maternity, race, religion or belief, sex, sexual orientation?

Negative

Please explain the reasons for your response. Where any negative impacts are identified, you may also wish to suggest ways in which these could be minimised or avoided.

The consultation document tells us that

Disability Rights Oregon has said that they have never “received a complaint that a person with disabilities was coerced or being coerced to make use of the Act”. (p16)

before reassuring us that:

¹⁹ journals.sagepub.com/doi/10.1177/1477750920907996

²⁰ [thetimes.co.uk/edition/scotland/assisted-dying-will-save-nhs-cash-and-provide-organs-argue-scottish-academics-h387gdn2q](https://www.thetimes.co.uk/edition/scotland/assisted-dying-will-save-nhs-cash-and-provide-organs-argue-scottish-academics-h387gdn2q)

²¹ [canada.ca/content/dam/hc-sc/documents/services/medical-assistance-dying-annual-report-2019/maid-annual-report-eng.pdf](https://www.canada.ca/content/dam/hc-sc/documents/services/medical-assistance-dying-annual-report-2019/maid-annual-report-eng.pdf)

²² [oregon.gov/oha/PH/PROVIDERPARTNERRESOURCES/EVALUATIONRESEARCH/DEATHWITHDIGNITYACT/Documents/year23.pdf](https://www.oregon.gov/oha/PH/PROVIDERPARTNERRESOURCES/EVALUATIONRESEARCH/DEATHWITHDIGNITYACT/Documents/year23.pdf)

²³ <https://pureportal.strath.ac.uk/en/publications/counting-the-cost-of-denying-assisted-dying>

Professor Ben Colburn (University of Glasgow, 2021) assessed the hypothesis that the disabled community would be negatively affected by an assisted dying law... the conclusion was that in no jurisdiction was there evidence that vulnerable people were subject to abuse, and the hypothesis that people with disabilities might be disproportionately impacted was not borne out. (p23)

We draw your attention to the US National Council on Disability's 2019 report, "Assisted Suicide Laws and their Danger to People with Disabilities."²⁴ In 1997, they had concluded:

that the interests of the few people who would benefit from assisted suicide were "heavily outweighed by the probability that any law, procedures, and standards that can be imposed to regulate physician-assisted suicide will be misapplied to unnecessarily end the lives of people with disabilities." Instead, NCD called for a comprehensive, fully-funded, system of assistive living services for people with disabilities.

By the time of the following report in 2005,

The nation had observed the implementation of the Oregon assisted suicide law, and the evolution of cultural attitudes toward so-called "mercy killing," of both the medical and non-medical variety. Jack Kevorkian was convicted of second-degree murder for committing active euthanasia of a man with ALS, utilitarian euthanasia advocate Professor Peter Singer was hired for a prestigious bioethics chair at Princeton University, two movies favorably depicting euthanasia of people with quadriplegia won Oscars, and numerous courts upheld the right of a guardian to starve and dehydrate a severely brain injured but healthy woman in Florida. The dangers to people with disabilities based on the devaluation of their lives was ever clearer.

The most recent report:

finds that the dangers and harms that NCD identified in 1997 and 2005 are at least as significant today. The report describes, among other things, a double standard in suicide prevention efforts where people with disabilities are not referred for mental health treatment when seeking assisted suicide, while people without disabilities receive such referrals. The report recommends steps that must be taken at the federal and state levels to ensure that people with disabilities have a system of assisted services and supports; that medical providers inform patients seeking assisted suicide of these supports; and that medical providers receive training in disability competency and disability-risk factors for suicide.

The NCD details the report's key findings:

Assisted suicide laws contain provisions intended to safeguard patients from problems or abuse. However, research for this report showed that these provisions are ineffective, and often fail to protect patients in a variety of ways, including:

Insurers have denied expensive, lifesustaining medical treatment but offered to subsidize lethal drugs, potentially leading patients toward hastening their own deaths.

Misdiagnoses of terminal disease can also cause frightened patients to hasten their deaths.

People with the disability of depression are subject to harm where assisted suicide is legal.

Demoralization in people with disabilities is often based on internalized oppression, such as being conditioned to regard help as undignified and burdensome, or to regard disability as an inherent impediment to quality of life. Demoralization can also result from the lack of options that people depend on. These problems can lead patients toward hastening their deaths—and doctors who conflate

²⁴ [ncd.gov/sites/default/files/NCD_Assisted_Suicide_Report_508.pdf](https://www.ncd.gov/sites/default/files/NCD_Assisted_Suicide_Report_508.pdf)

disability with terminal illness or poor quality of life are ready to help them. Moreover, most health professionals lack training and experience in working with people with disabilities, so they don't know how to recognize and intervene in this type of demoralization.

Financial and emotional pressures can distort patient choice.

Assisted suicide laws apply the lowest culpability standard possible to doctors, medical staff, and all other involved parties, that of a good-faith belief that the law is being followed, which creates the potential for abuse.

There is a substantial lack of data about assisted suicide, due not to lack of research, but to unnecessarily strict privacy and confidentiality provisions in assisted suicide laws.

Where assisted suicide is legal, states have no means of investigating mistakes and abuse, nor even a complaint mechanism or similar way for the public to report suspected problems.

Nevertheless, a few important conclusions can be gleaned from the minimal available data, including that assisted suicide laws require no evidence of consent when the lethal drugs are administered.

Trends show that the minimal amount of data collection that was mandated by earlier state laws is decreasing over time as some newer states adopt less restrictive assisted suicide laws.

Regarding the protected characteristic of age, the consultation acknowledges that:

Healthcare practitioners are increasingly encountering older adults expressing wishes to end their life. Research and data collected from permissive jurisdictions shows that assisted dying is likely to be used disproportionately by older people, as these are the people most likely to be diagnosed with a qualifying terminal illness. However, the Bill makes access to assisted dying equally available to adults (over-16s) of any age. (p22)

We would point to ongoing efforts²⁵ in the Netherlands to extend the law there to older people who are tired of life even if they are comparatively healthy. This proposal's definition of "terminally ill" is already so broad as to likely cover most older people living with multiple, manageable, age-related health conditions which will, eventually, contribute to their deaths.

Children are a different matter. The proposal is based on a requirement that patients be at least 16 years of age; it is worth noting that the Netherlands' euthanasia law has from its inception made provision for children as young as 12, with 12-15 year olds requiring parental agreement and 16-17 year olds requiring parental consultation – Scotland would already be stepping beyond international precedent. Of course, Belgium chose to extend its law (originally only for those over 18) for children of all ages in 2014.²⁶ When Canada's extension of euthanasia to non-terminally ill people received Royal Assent on 17 March 2021, the new law required:

An independent review to be carried out by experts respecting recommended protocols, guidance and safeguards to apply to requests made for medical assistance in dying by persons who have a mental illness. A report containing the experts' conclusions and recommendations must be provided to the Ministers no later than the first anniversary of the day on which this Act receives royal assent...

A comprehensive review of the provisions of the Criminal Code relating to medical assistance in dying and their application, including but not limited to issues relating to mature minors, advance requests, mental illness, the state of palliative care in Canada and the protection of Canadians with disabilities must be undertaken by a

²⁵ dutchnews.nl/news/2019/09/d66-to-press-ahead-with-bill-to-support-assisted-suicide-for-completed-lives/

²⁶ carenotkilling.org.uk/articles/first-minor-euthanised-in-belgium/

*Joint Committee of both Houses of Parliament... The Committee must submit a report of its review — including a statement of any recommended changes — to Parliament no later than one year after the day on which it commenced the review.*²⁷

Canada had already been preparing for an age-based broadening of euthanasia legislation. Writing²⁸ in the *BMJ Journal of Medical Ethics* in 2018, Carey DeMichelis, Randi Zlotnik Shaul and Adam Rapoport (doctors associated with a Toronto children's hospital) considered whether age or capacity should be the dividing line for accessing euthanasia, whether doctors should be required to bring MAID to young patients' attention, whether children should be able to undergo euthanasia without their parents' knowledge – much less their consent – and whether hospitals have a responsibility to normalise euthanasia.²⁹

There is no reason to believe that a Scottish law would not be susceptible to age-based expansion in the name of equality and autonomy.

Sustainability

9. In terms of assessing the proposed Bill's potential impact on sustainable development, you may wish to consider how it relates to the following principles:

- **living within environmental limits**
- **ensuring a strong, healthy and just society**
- **achieving a sustainable economy**
- **promoting effective, participative systems of governance**
- **ensuring policy is developed on the basis of strong scientific evidence.**

With these principles in mind, do you consider that the Bill can be delivered sustainably?

No

Please explain the reasons for your response.

This proposal and much of its underpinning thesis cannot possibly serve to nurture a “healthy and just society”.

It is claimed on page 4 that “an outright prohibition does not work and that we cannot continue to tolerate a situation where the options open to people at the end of life are so limited.” We have already referenced polling showing confusion over what constitutes ‘assisted dying’, and public misunderstandings about what is available. We hear regularly from doctors that patients often do not understand what care and support will be available, but that requests for assisted suicide almost always recede once such support and care is experienced.³⁰ Arguably, the first focus should be on campaigning to highlight existing options which include *where* you receive treatment or care, *whether* you try new treatments or discontinue others, and *who* you are surrounded by.

The consultation document rightly states that:

A fundamental aspect of sustainable development is ensuring that economic, cultural and political systems do not favour some people while harming others. (p27)

²⁷ laws-lois.justice.gc.ca/eng/AnnualStatutes/2021_2/page-1.html

²⁸ jme.bmj.com/content/early/2018/09/21/medethics-2018-104896

²⁹ carenotkilling.org.uk/articles/canada-plans-for-child-euthanasia/

³⁰ youtube.com/watch?v=oG72jjy_QbM

having already asserted that:

The proposal presented in this Consultation is one that co-exists with support for more and better palliative care and applies only to terminally ill, mentally competent adults. (p3)

These points run into trouble when we strike upon another inconvenient “however”:

*We recognise that people with disabilities continue to face social stigma, inequalities in access to public life, and a lack of adequate support for basic social, economic, and civic participation. Those problems need urgent attention, and legalising assisted dying alone will not deal with broader problems to do with funding and support for social care and disability support. **However**, it is possible to advocate for greater resourcing for those provisions whilst also increasing the choices available at the end of life... [and] it would be a mistake to “oppose legalising assisted dying until those wider problems are fixed. For one thing, changes in the law to allow assisted dying, perhaps precisely by drawing attention to that wider context, can go hand in hand with developments that improve other aspects of end-of-life care. It bears repeating that there is no tension between assisted dying and a well-supported palliative care regime for patients who do not seek to end their lives.*

The suggestion of campaigning for palliative care access and assisted suicide in tandem quickly gives way to not letting the former hold up the latter.

The consultation implicitly concedes that many who would benefit do not have access: “even if every dying person who needed it had access to high quality, specialist palliative care in Scotland...” MSPs know that:

Around 80% of all people who die in Scotland can benefit from some form of palliative care such as hospice care, yet every year 11,000 people are dying without this care.³¹

Legalising assisted suicide before ensuring equitable access to fully-funded palliative care, and adequate financial support for dignity in living, is an affront to a “healthy and just society.”

The proposal “seeks to give peace of mind, comfort, and reassurance to those who need it most i.e. those who are suffering and dying” (p5) and acknowledges that “the process of arranging an assisted death overseas is extremely distressing and one which puts additional pressure on the person who is already suffering from a terminal illness” (p27). It does not acknowledge the pressure placed on patients by the ever-present option of burden-relieving early death. Professor Theo Boer, a Dutch ethicist and former euthanasia regulator, addressed MSPs on this point in 2021, referring to the “dilemma of the choice”³², and Archbishop Justin Welby wrote in 2014³³ that:

Abuse, coercion and intimidation can be slow instruments in the hands of the unscrupulous, creating pressure on vulnerable people who are encouraged to “do the decent thing”. Even where such pressure is not overt, the very presence of a law that permits assisted suicide... is bound to lead to sensitive individuals feeling that they ought to stop “being a burden to others”. What sort of society would we be creating if we were to allow this sword of Damocles to hang over the head of every vulnerable, terminally ill person in the country?

The proposal foresees a “Scotland-wide information campaign to raise awareness of the change in the law” (p28); would we see, as Canadian citizens have, advertisements for euthanasia in A&E waiting rooms?³⁴

The consultation notes that “people living with terminal illness have an increased likelihood of attempting to end their own life, and many do, often alone and in traumatic circumstances... As a country, we must do better by our

³¹ ehospice.com/uk_posts/moves-to-widen-access-to-palliative-care-in-scotland/

³² youtube.com/watch?v=sEH2qH9R1G4

³³ thetimes.co.uk/article/helping-people-to-die-is-not-truly-compassionate-gh8ffcllrk

³⁴ nationalreview.com/corner/canadian-hospital-waiting-room-promotes-euthanasia/

dying citizens.” (p11). This consultation document shows no interest in a suicide prevention campaign aimed at terminally ill people, or research into how better to meet existential concerns and unmet symptom control – the interest is in standardising and easing access to suicide. Nor does it consider the link between terminal illness and clinical depression.

The document’s authors contend that:

The requirement to be physically able to travel abroad to have an assisted death means that people are ending their lives much sooner than they might otherwise choose to, thus denying them precious time with their loved ones. (p27)

This avoids evidence from jurisdictions like Oregon showing that patients regularly far outlive their six-month prognoses before ingesting the lethal prescriptions, reminding us of the unreliability of prognoses and suggesting that those who ingested after a short time could easily have significantly foreshortened their lives. This proposal does not include a specific life expectancy, but the mention of people “ending their lives much sooner than they might otherwise choose to” places the emphasis firmly on autonomy rather than closeness to death as argued by Mr McArthur in the foreword and highlighted already in this submission. This law would undermine suicide prevention, and in no way resolve the issue of people dying sooner by travelling abroad for assisted suicide – it would simply shift sideways, to people newly exposed to this appalling “choice”.

The consultation discusses the significant financial cost of undergoing assisted suicide abroad before stating:

The Bill will particularly increase choice for those on lower incomes, given that the only current equivalent (travel to an organisation such as Dignitas in Switzerland) is expensive and so affordable only to the better-off. (p27)

Studies such as Marie Curie’s “The cost of dying: The financial impact of terminal illness” have made clear that living with a terminal illness comes with a huge personal financial cost: two-thirds of households affected by terminal illness experience financial strain as a result, and disadvantaged families can spend as high as of their income on the added costs brought on by terminal illness.³⁵ Ensuring access to assisted suicide for those who are not only less well-off but worst-hit financially by *living* with their illnesses, before ensuring equitable access to palliative care, is intolerable.

If we consider a “strong, healthy and just society” as founded on human rights obligations, it is relevant that Mr McArthur notes:

The Bill proposal has implications for human rights under ECHR – particularly Article 2 (right to life) and Article 8 (right to respect for private and family life) and Article 14 (with Article 2 or 8) (protection from discrimination). (p27)

We, Care Not Killing, have intervened in a number of court cases adjudicating the balance of these same articles in the context of assisted suicide, including in the case of Mr Noel Conway. The Court of Appeal upheld (in 2018) the 2017 ruling of the Divisional Court 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 the 1961 Suicide Act, banning assisted suicide]

³⁵ mariecurie.org.uk/globalassets/media/documents/policy/policy-publications/2019/00962-cost-of-dying_financial-impact-report.pdf

*is compatible with the Article 8 rights of Mr Conway. We dismiss his application for a declaration of incompatibility.*³⁶

Although the 1961 Suicide Act does not apply in Scotland, the principles lying behind those courts' judgement do apply to the common law in Scotland.

With reference to the *clarity* of the law in Scotland, we note the opinion of Lord Carloway in Ross:

*The concepts of Scottish criminal law that are relevant to assisted suicide are murder and culpable homicide. The essence of those concepts is reasonably clear; it emerges from a large number of decided cases... absolute certainty is impossible, but it is clear in my opinion that the standard of reasonable certainty has been reached... In relation to assisted suicide, the Prosecution Code is supplemented by the statements by the Lord Advocate and Crown Office to the Health and Sport and Justice Committees of the Scottish Parliament. These indicate that the Lord Advocate attaches importance to the serious nature of homicide, and that if sufficient evidence exists the normal course of action will be a prosecution. The statements of policy make it clear that exceptional cases may exist where a prosecution will not be appropriate; in such cases the general discretion of the prosecution authority will be relevant. Nevertheless, it is apparent that the norm is to prosecute. It is of the nature of exceptional cases that they are hard to predict. To expect an enumeration of such cases would be wholly unreasonable. For this reason I am of the opinion that the Lord Advocate's policy clearly meets the standard of reasonable certainty that is implicit in the requirement of legality in article 8(2).*³⁷

We assert that the present law provides for a level of discretion that is both sufficient and necessary in order to protect against abuse while permitting for compassion in particular cases. To reiterate, it is clear to us, as it has been to a litany of judges, that a prohibition on assisted suicide is compatible with the ECHR.

General

10. Do you have any other additional comments or suggestions on the proposed Bill (which have not already been covered in any of your responses to earlier questions)?

There are a great many conclusions we could lay out, but we will focus on a passage from page 3:

Emerging from the pandemic, we have an opportunity to take the actions required to make sure that the end of life is more compassionate, fairer and more reflective of a dying person's choice. We have the ability to create a new standard for how we die.

It is clear to us that the proposal placed before the Scottish Parliament would indeed set a new standard, but only by lowering the bar. The proposal would add a cheap "treatment option" without first ensuring equitable access to life-changing palliative care, and create a two-tier approach to suicide prevention: some lives henceforth will be worthy of saving, their suicides prevented, but once an individual is given a certain diagnosis, the state will consider their suicides to be reasonable and worthy of facilitation. Specific mention has been made of the experience of Covid 19, in the course of which we have seen healthcare professionals go above and beyond to fight for patients, but we have also seen DNACPRs applied to older and seriously ill patients, and people with learning disabilities, without individual assessment or consent. We also saw many elderly people being discharged into care homes without first being tested for Covid 19. There are ongoing legal proceedings resulting from this experience with allegations of Articles 2, 8 and 14 of the ECHR having been violated. The lessons of this pandemic should be to strive for innovation in saving and

³⁶ carenotkilling.org.uk/articles/high-court-rules-on-conway/

³⁷ scotcourts.gov.uk/search-judgments/judgment?id=363108a7-8980-69d2-b500-ff0000d74aa7

valuing each individual, and to reject easy value judgements. This proposal's counsel of despair should be rejected by the Scottish Parliament, with instead a renewed focus on ensuring equitable access to life-changing palliative care and support for living.