

Written evidence submitted by Not Dead Yet UK (ADY0485)

This submission is made on behalf of Not Dead Yet UK (NDYUK). We are a network of disabled people in the UK, part of a growing international alliance, who oppose the legalised killing of disabled people. The network is managed and controlled by disabled people and their supporters. Our members include people with physical and sensory impairments, learning difficulties and mental health conditions.

We welcome the opportunity to contribute to this inquiry. Our submission addresses the issues in questions 2, 3 and 8 of your terms of reference:

- Lessons from the evidence in countries where assisted dying/assisted suicide is legal
- Professional and ethical considerations in allowing physicians to assist someone to end their life
- The Government's role in this debate

We address those issues through the prism of disability and in the context of the barriers placed on disabled people by society.

Note on terminology

- For brevity, we refer to 'assisted dying/assisted suicide' as 'assisted death'.
- In our view, 'assisted dying' is a misnomer: it is in reality assisted suicide.
- When we refer to 'disabled people' it includes people with a long-term health condition.
- We refer to 'control' instead of 'autonomy' as that is the word disabled people use.

Our headline points

- Evidence of 'legislation creep' in countries where assisted death is legal suggests a similar risk if the law is changed here.
- The restrictions society places on disabled people denies them true choice and control.
- In the absence of choice and control, the role of physicians in assisting a disabled person to take their life cuts across the principle of informed consent.
- Assisted suicide legislation conveys the message that living with a disability is a fate worse than death.
- The Government's role is to increase resources for palliative care, improve support for disabled people and uphold its commitment to enabling their full participation in society.

The disability context

Despite repeated attempts to legalise assisted death¹ in the UK, none of them has yet succeeded, primarily because of the risks to the vulnerable population. This illustrates that there are fundamental problems with such legislation.

The barriers faced by disabled people

¹ [Marris, R. 2016. Assisted Dying \(No. 2\) Bill. UK Parliament;](#) [Meacher, M. 2021. Assisted Dying Bill \(House of Lords\). UK Parliament.](#)

The questions we address in this submission have to be seen in the context of the barriers that disabled people experience daily². They are far-reaching and cover all aspects of life. For example, disabled people struggle to access social security, sufficient health and social care support and suitable housing, and to participate in education, the labour market and their communities. These barriers are unnecessary and are due to the way society is organised. We believe this contributes to depression and feelings of hopelessness experienced by many disabled people. Assisted death is often viewed as a solution to their social and economic situation, albeit caused by external factors.

The social model

The UK government has set out its commitment to the social model of disability³, focusing on removing the barriers in society to enable the full participation of disabled people. This means building accessible environments, challenging negative attitudes towards disabled people, and ensuring that legislation and policy measures prioritise inclusion and participation⁴. We believe assisted suicide legislation will undermine attempts to realise these commitments. It will divert attention from addressing the barriers in society to resolving the individual's situation through death. Ultimately, passing assisted suicide legislation will convey a message that living as a disabled person is a fate worse than death.

Q2: What can be learnt from the evidence in countries where assisted death is legal?

Legislation creep

The most significant and concerning lessons from countries which have existing legislation are the attempts to broaden the eligibility criteria once the legislation is in place. The evidence is widespread:

- A. Assisted deaths increased by 182% in the Netherlands⁵ between 2002 and 2014 in cases associated with dementia and mental health⁶. The 2002 law in the Netherlands refers to ending 'unbearable suffering'. However, legalisation of euthanasia has normalised physician-assisted death and expanded its practice.⁷ It now includes euthanasia for new-born babies and children up to 12 years old⁸. It has also extended the scope from voluntary to non-

² Griffiths, M. 2022. Disabled youth participation within activism and social movement bases: An empirical investigation of the UK Disabled People's Movement. *Current Sociology*; 0(0). <https://doi.org/10.1177/00113921221100579>

³ Secretary of State for Work and Pensions. 2021. National Disability Strategy. HM Government.

⁴ inclusion London. 2023. The Social Model of Disability. [Online]. Available at: <https://www.inclusionlondon.org.uk/about-us/disability-in-london/social-model/the-social-model-of-disability-and-the-cultural-model-of-deafness/>

⁵ Regional Euthanasia Review Committees. 2019. Annual reports. [Online]. Available at: <https://english.euthanasiecommissie.nl/the-committees/documents/publications/annual-reports/2002/annual-reports/annual-reports>

⁶ Emanuel E.J., Onwuteaka-Philipsen B.D., Urwin J.W., Cohen J. 2016. Attitudes and Practices of Euthanasia and Physician-Assisted Suicide in the United States, Canada, and Europe. *JAMA*; 316(1):79–90. [doi:10.1001/jama.2016.8499](https://doi.org/10.1001/jama.2016.8499)

⁷ Koopman, J.J.E. and Boer, T.A. 2016. Turning points in the conception and regulation of physician -assisted dying in the Netherlands, 129, 8, 773-775. <https://doi.org/10.1016/j.amjmed.2016.02.025>

⁸ Catlin, A. and Novakovich, R. 2008. The Groningen Protocol: What Is It, How Do the Dutch Use It, and How Do We Use It Here?. [Online]. Available at: <https://www.proquest.com/openview/2f5f978f061e5f38e3bf34c2b4e06d50/1?pq->

voluntary euthanasia, including cases of dementia⁹ where patients are incapable of giving consent, and chronic psychiatric patients: there were no cases in 2009 but 60 in 2016¹⁰.

- B. A study in Belgium in 2010 found that in half the cases in Flanders involving assisted suicide, doctors did not report the death to the review committee, as required. 14% of them said they didn't report it because they suspected the legal requirements had not been met, or they feared possible legal consequences¹¹.
- C. In Spain assisted suicide and euthanasia legislation was used to permit an alleged perpetrator to die prior to his court trial¹².
- D. There was a 344% increase in assisted deaths in Oregon, United States¹³ between 1998 and 2011.
- E. Canada's assisted deaths legislation, which includes euthanasia, has been amended several times. In 2016 it was broadened to include 'individuals who have a grievous and irremediable medical condition'. It required four criteria to be met, one of which was that natural death was reasonably foreseeable.
- F. In 2020 following consultations, the requirement for natural death to be reasonably foreseeable was removed, allowing a person whose sole medical condition is mental illness to access assisted death from March this year (though the effective date may, apparently, be deferred).
- G. UN human rights experts expressed grave concern in 2021 about State-sanctioned legislation allowing access to assisted death for those who are not terminally ill¹⁴.
- H. Canada's legislation has led to varying levels of procedural safeguards. In effect, the law is flexibly interpreted to fit the individual case, expanding the range of circumstances in which access to death can occur¹⁵.

The implications of incremental change

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⁹ [Schuurmans, J., Bouwmeester, R., Crombach, L. et al. 2019. Euthanasia requests in dementia cases; what are experiences and needs of Dutch physicians? A qualitative interview study. BMC Med Ethics 20, 66. <https://doi.org/10.1186/s12910-019-0401-y>](#)

¹⁰ [Dierickx, S., Deliens, L., Cohen, J. et al. 2017. Euthanasia for people with psychiatric disorders or dementia in Belgium: analysis of officially reported cases. BMC Psychiatry 17, 203. <https://doi.org/10.1186/s12888-017-1369-0>](#)

¹¹ [Smets, T., Bilsen, J., Cohen, J. 2010. Reporting of euthanasia in medical practice in Flanders, Belgium: cross sectional analysis of reported and unreported cases. BMJ, 341, <https://doi.org/10.1136/bmj.c5174>.](#)

¹² [Lopes, S. 2022. Spain allows man to be euthanised ahead of trial for attempted murder. The Washington Post.](#)

¹³ [Shariff, M.J. 2012. Assisted Death and the Slippery Slope—Finding Clarity Amid Advocacy, Convergence, and Complexity. Current Oncology, 19, no. 3: 143-154. <https://doi.org/10.3747/co.19.1095>](#)

¹⁴ <https://researchbriefings.files.parliament.uk/documents/POST-PB-0047/POST-PB-0047.pdf>

¹⁵ [Downie, J. 2022. From Prohibition to Permission: The Winding Road of Medical Assistance in Dying in Canada. HEC Forum 34, 321–354. <https://doi.org/10.1007/s10730-022-09488-6>](#)

There have been disturbing accounts recently¹⁶ about the way the assisted death regime in Canada is working. Canadians were promised a system that would distinguish a rational choice to die from a desperate cry for help (when they would be encouraged to live with the right support in place).

That balance is proving fragile, with evidence of less than subtle suggestions about the availability of assisted death, inadequate assessments, doctor shopping and weak enforcement. The comparison with California (which introduced its legislation in the same year as Canada and has a similar sized population) is instructive. In 2021 486 people died under its assisted death regime, in Canada 10,064.

We believe there is a risk of legislative creep in this country if assisted death legislation is introduced. The evidence in other countries indicates a global trend to broaden eligibility criteria. Although this has led some states to reassess the implications of that, the dominant campaigns in the UK advocating a change in the law provide ample evidence that a similar outcome could ensue here.

There are divergencies between the campaigns¹⁷ because the dominant campaigners have different impairments and capacities which affect their capabilities and expectations. If assisted death legislation is introduced it is unlikely to satisfy the demands of all the campaigns. That would lead to further campaigning and potential broadening of the coverage.

Q3: What are the professional and ethical considerations involved in allowing physicians to assist someone to end their life?

Choice and control

Choice and control are universally important principles that should be valued and respected. This is crucial for marginalised communities, such as disabled people, who want choice and control over their lives like everyone else in society. They do not currently have the same choices as to how and where to live their lives¹⁸. However, the concept of choice and control cannot be used to justify the introduction of assisted suicide legislation¹⁹ for two reasons.

Control may be limited

The principle of control is not absolute. Governments may limit individual liberty in some circumstances to protect certain people or communities on the grounds of health or morality (for example, on access to recreational drugs). We believe that assisted suicide is an example of where governments must override the principle of control to protect marginalised communities, particularly disabled people, given their profound concerns.

Autonomy requires informed choice

¹⁶ <https://www.thenewatlantis.com/publications/no-other-options>

¹⁷ [Dignity in Dying. 2023. Personal stories. \[Online\]. Available at: https://www.dignityindying.org.uk/why-we-need-change/personal-stories/](https://www.dignityindying.org.uk/why-we-need-change/personal-stories/)

¹⁸ [Olsen, J. 2018. Socially disabled: the fight disabled people face against loneliness and stress. Disability & Society; 33:7, 1160-1164, DOI: 10.1080/09687599.2018.1459228](https://doi.org/10.1080/09687599.2018.1459228)

¹⁹ [Frost, T.D.G., Sinha, D. & Gilbert, B.J. 2014. Should assisted dying be legalised?. Philos Ethics Humanit Med 9, 3. https://doi.org/10.1186/1747-5341-9-3](https://doi.org/10.1186/1747-5341-9-3)

To have true control, individuals need sufficient information to weigh up the choices before them and make rational decisions. This is the basis of informed consent. That is why it is a fundamental duty of a doctor to offer patients informed treatment options. But doctors aren't able to advise patients as to when their situation will be preferable to being dead because they don't know what death is like. So the concept of having control through informed consent is, in practice, illusory.

Disabled people experience restricted choices in their daily lives²⁰, especially in getting the support they need for their health and well-being²¹. They struggle to acquire accessible housing, have poorer ratings on all well-being measures, including anxiety levels, and feel significantly more lonely. This undoubtedly affects their choices as to how to live their life and whether it is worth living.

Attitudes towards disabled people

Contemporary data shows that public perceptions of disabled people remain a significant barrier to their participation in society²².

The findings illustrate some of the struggles disabled people experience – notably, on isolation, unfairness, and low levels of life satisfaction. These issues are of greater concern in the context of assisted suicide because they affect people's decisions. The data indicates that these experiences are often one of the motivations for pursuing assisted death.

Evidence from palliative care specialists reveals that most people who seek assisted suicide say that 'not wanting to be a burden' is the main reason for seeking death²³. This is also borne out by the evidence from abroad.

In 59% of assisted suicides in Oregon in 2019, being a 'burden on family, friends or caregivers' was quoted as one of the main reasons for requesting it²⁴. 34% of those who were euthanised in Canada in 2019 cited 'perceived burden on family, friends or caregivers' as a prime reason²⁵. Long-term studies in the United States also show that the two most common end-of-life concerns are loss of autonomy and the ability to participate in enjoyable activities²⁶.

Q8: What should the Government's role be in relation to the debate?

²⁰ [Crowther, N. 2019. Living independently and being included in the community. Academic network of European Disability Experts.](#)

²¹ [Rabiee, P. 2013. Exploring the Relationships between Choice and Independence: Experiences of Disabled and Older People, The British Journal of Social Work, Volume 43, Issue 5, 872–888, <https://doi.org/10.1093/bjsw/bcs022>](#)

²² [Disability Unit. 2021. UK Disability Survey research report, June 2021. \[Online\]. Available at: <https://www.gov.uk/government/publications/uk-disability-survey-research-report-june-2021/uk-disability-survey-research-report-june-2021#quantitative-insights>](#)

²³ [Hoffenberg, R. 2006. Assisted dying. Clinical Medicine, 6 \(1\) 72-74; DOI: 10.7861/clinmedicine.6-1-72.](#)

²⁴ [Oregon Health Authority Public Health Division, 2020. Center for Health Statistics Date. State of Oregon.](#)

²⁵ [Government Of Canada. 2019. First annual report on medical assistance in dying in Canada, 2019. \[Online\]. Available at: <https://www.canada.ca/en/health-canada/services/medical-assistance-dying-annual-report-2019.html>](#)

²⁶ [Shariff, M.J. 2012. Assisted Death and the Slippery Slope—Finding Clarity Amid Advocacy, Convergence, and Complexity. Current Oncology, 19, no. 3: 143-154. <https://doi.org/10.3747/co.19.1095>](#)

We believe the Government's role should be to retain the status quo on assisted death. To do otherwise would be incompatible with its commitment to support the social model and the full participation of disabled people in society.

Priority areas

The Government should focus on the key priorities needed to improve disabled people's lives and mitigate the negative attitudes towards them. That means providing the support they need particularly during end-of-life care, for example by:

- A. securing sufficient, non-means tested, personalised support to enable disabled people to participate in their communities.
- B. increasing resources to palliative care, particularly palliative care in the community.
- C. ensuring that health and social care policy investigates the health inequalities experienced by disabled people in the UK. They must identify the barriers, and invest in the development of solution-focused plans to remove them.
- D. initiating research, via the Disability Unit in the Cabinet Office, in which disabled people are centrally involved, to explore the implications of assisted death legislation on disabled people's communities.

Conclusion

This submission outlines the detrimental impact of state-sanctioned assisted death. It has drawn on extensive research, including civil society reports and media publications.

There is irrefutable evidence from abroad that, once adopted, the scope of such legislation is open to expansion well beyond the original intention.

It would undermine attempts to remove the societal barriers that preclude disabled people from fully participating in their communities, putting the emphasis back on the individual. That would reinforce the damaging notion that disabled lives are not worth living.

The Government's role is to maintain its commitment to disabled people's right to full participation in society and not to jeopardise that commitment by supporting a change in the law. It should focus its attention on remedying the inequalities to remove the existing barriers.

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