

Written evidence submitted by Martin Stevens OBE (ADY0286)

I am a Disabled Person living with Multiple Sclerosis, and the former chair of Disability Rights UK, I wish to submit evidence to the Committee in support of law change to allow terminally ill mentally competent adults the option of an assisted death. My support is based on overseas evidence that these safeguards enable the protection of potentially vulnerable people, and that is the legislative model that would work for Disabled People in the UK.

Public support

- Polling has shown that 86% of people living with a disability support assisted dying being a choice for terminally ill people¹
- A recent survey of disability rights organisations in the UK indicated a wide diversity of stances and policies on the question of assisted dying. Of 140 such organisations surveyed, a substantial majority either remain silent (84%) or explicitly endorse neutrality (4%) on assisted dying. Only 4% explicitly oppose it.²
- *As a supporter of disability rights, I back the right of Disabled People to have control over the time and manner of their death when they are terminally ill, so they can avoid unbearable suffering and achieve dignity in dying. Being disabled in itself is no reason to die, but for many of those who have terminal illness, controlling the circumstances of their death becomes very important*
- Sir Tom Shakespeare³

Overseas evidence

- Disability Rights Oregon, an organisation committed to protecting Oregonians living with disabilities, has never received a complaint of abuse or attempted abuse under Oregon's law - <https://compassionandchoices.org/letter-from-disability-rights-oregon-dro/>
- In Victoria Australia and in New Zealand, disability activists were deeply involved in the crafting of the law and in overseeing it.

For example, Philip Patston who lives with cerebral palsy argued that *"we land in dangerous territory when we try to protect one group by denying the rights of another. Both disabled people and those with terminal, incurable, illness deserve the right to choice and autonomy."* He is now on the statutory body for the assisted dying service in New Zealand.⁴

Tricia Malowney, a disability activist and advocate and a member of the Victorian ministerial advisory panel on voluntary assisted dying observed: *The concerns of the disability community have been met, through the inclusion in the bill that merely having a disability will not meet the eligibility criteria, an acknowledgment that all lives have equal value and that we have the same rights and responsibilities as other Victorians.*⁵

¹ Populus 2019

² Box G, Chambered K. J Med Ethics 2021;0:1–7. doi:10.1136/medethics-2020-107021

³ <https://www.theguardian.com/commentisfree/2009/jul/07/assisted-dying-terminally-ill-disabled>

⁴ <https://www.diversitynz.com/blog/philip-s-blog-not-all-disabled-people-are-afraid-of-assisted-dying> and <https://www.health.govt.nz/our-work/life-stages/assisted-dying-service/support-and-consultation-end-life-new-zealand-scenz-group>

⁵ <https://www.theguardian.com/commentisfree/2017/oct/17/as-people-with-disabilities-we-shouldnt-be->

- Systematic reviews have examined the uptake of assisted dying amongst vulnerable people, including people with disabilities. One concluded that the hypothesis that people with disabilities might be disproportionately impacted ‘does not seem to be borne out’, and that ‘in no jurisdiction was there evidence that vulnerable patients have been receiving euthanasia or physician-assisted suicide at rates higher than in the general population... data do not indicate widespread abuses of these practices.’⁶

The need for change

- Current end-of-life practices have far more potential for abuse and harm for disabled people (e.g. outsourcing the problem to Dignitas and doctors making decisions without transparency or oversight) compared to the upfront safeguards that exist under the assisted dying laws operating safely in the US, Australia and New Zealand.
- An assisted dying law will provide protection for Disabled People because, unlike current end of life care practices which often don’t need a person’s consent (palliative sedation, DNACPR) assisted dying requires the person to request it and have the mental capacity to do so.
- I witnessed first-hand the harrowing death of my mother in law from Motor Neuron disease. She went into hospital on Christmas Eve and then transferred to a hospice. She was using a ventilator and tube fed. She was in so much distress and wanted it to stop, her only option was to stop being fed by the tube, which is a slow and unpleasant way to die. Trying to do this by removing the ventilator was equally distressing. She died mid-January, heavily sedated, starving and suffocating and unable to say farewell. Truly horrible, affecting her whole family. She had brilliant and exemplary palliative care in the Hospice but despite this, still died a slow and unpleasant death.
- We can and must work to improve the support systems available to Disabled People, enabling them to live well. We can and must also have the courage to draft legislation which will give dying people meaningful choice at the end of their lives.
- The argument for assisted dying is fundamentally about giving people choice and control at the end of life. I have campaigned in support of Disabled People having choice and control in their lives and want to see it being offered terminally ill people at the end of life too.

[denied-access-to-assisted-dying](#)

⁶ Emanuel, E.J. et al. (2016) Attitudes and Practices of Euthanasia and Physician Assisted Suicide in the United States, Canada, and Europe, JAMA 316:79-90.

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