

## Written evidence submitted by Tom Shakespeare (ADY0021)

I write as one who has spent his career as a social researcher in listening to disabled people's views. I also write as one active in bioethics debates who is unusual in being a disabled advocate who supports assisted dying for terminally ill people. However, while few of us speak out for assisted dying, the evidence shows that disabled people broadly echo non-disabled people's opinions. If anything, the evidence shows that more disabled people support assisted dying than oppose.

To be clear, I support assisted dying for terminally ill people (like those American states who have passed assisted dying laws, including Oregon, Washington, Montana etc) not on the grounds of irredeemable suffering (as Belgium, Netherlands and Canada have done). I believe there is minimal risk in allowing people who are terminally ill to have a death that comes a few days or weeks earlier than their natural death. In opting for assisted dying, people in this category are deciding *how* they will die, not *when* they will die. But there is considerable risk in making death possible for people who would otherwise have lived for many more years or even decades, and who may have experienced a restoration of quality of life as they adapt to their restrictions or discover independent living supports in the community. The two situations are by no means equivalent. In the former case, a person gets a better death than they would otherwise have done; in the latter case, someone's opportunity to lead a meaningful life is forever removed.

The restriction to the condition of terminal illness has also been advocated by many, but not all, scholars<sup>1</sup> who have discussed the matter. The various attempts to liberalise the law in the United Kingdom – for example the Private Members' Bills introduced in the House of Lords by Lord Joffe, Lord Falconer and others - have all made the key distinction between end of life situations versus non-terminal stage situations of illness and impairment. The restriction to the condition of terminal illness was also the position of the UK Commission on Assisted Dying, which recommended that non-terminally ill persons with significant physical impairments should not be eligible. This distinction was made partly as a response to evidence submitted by many disabled people:

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<sup>1</sup> E.g. T.Quill. *A Midwife Through the Dying Process: stories of healing and hard choices at the end of life*. Baltimore, Johns Hopkins University Press, 1996. See also M. Gunderson and D.J. Mayo. Restricting physician-assisted death to the terminally ill. *Hastings Center Report* 2000, 30, 6: 17-23.

“The intention of the Commission is to... establish a clear delineation between the application of assisted suicide for people who are terminally ill and others with long-term conditions or impairments. The adoption of this distinction in any future legislation would send a clear message that disabled people’s lives are valued equally.”<sup>2</sup>

I was a government expert witness in the Truchon case in Quebec, where plaintiffs sought, successfully, to extend the right of assisted dying to all people who experienced irredeemable suffering, regardless of whether death was “reasonably foreseen”. Exactly what we warned about has resulted: disabled people have sought death because social services were inadequate to meet their needs.

New-onset impairment can be a great tragedy, whether it comes about through traumatic accident or a disease such as MS. Almost everyone has grief and suicidal ideation – and here I would include myself, after I developed spinal cord injury in August 2008. However, the evidence is that people adapt to paralysis or other new impairments, and almost always lead a good, happy and productive life, with the right assistive technology, accessible accommodation, and personal assistance where needed. Society and the state should make these benefits available to everyone in need, rather than rationing or otherwise making them unavailable.

I do not think that better services solve problems for terminally ill people, because they have less than a year to live. Nor do I think that people are vulnerable to pressure from relatives or health and social care. The evidence is that others are more likely to reject a person’s wish for assisted suicide than push people towards it. I do believe in the importance of safeguards – a cooling off period, needing two medical practitioners to endorse a request, to not be in a state of depression or other compromised autonomy – but, assuming these are present, I think it is rational for people to want to control the timing and manner of their death, if terminally ill. Evidence shows that more people will request the right than will exercise it: assisted dying in this sense is an insurance against a bad death.

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<sup>2</sup> Report of the Commission on Assisted Dying, p.27. <https://www.demos.co.uk/project/the-commission-on-assisted-dying>  
See also: <http://www.commissiononassisteddying.co.uk/>

Therefore, as an advocate for independent living and disability rights, I do not think it at all inconsistent also to be advocate for legislation permitting assisted dying for those who are terminally ill. We deserve a good life, with us in control; we also deserve a good death, with us in control.

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