

## Assisted suicide: a disability perspective

The draft bill soon to be introduced into the NSW Parliament is to legalise assisted suicide for persons who are 'experiencing severe pain, suffering or physical incapacity to the extent unacceptable to the patient'.

This proposal for assisted suicide raises profound concerns about its implications for people living with disabilities in New South Wales.

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### BETTER OFF DEAD

The proposed model would require two doctors to agree to a person's request for a prescription for a lethal dose to be used to end the person's life. To do so the doctors essentially need to agree that the person would "be better off dead" or at least that it is reasonable for a person in that position to consider that he or she would be better off dead.

The reasons given for requesting assisted suicide in Oregon are **not primarily to do with pain** (only 26.4%) but rather (only 26.4%) with concerns about loss of autonomy (91.4%), decreasing ability to participate in activities that made life enjoyable (89.7%), loss of dignity (77%), loss of control of bodily functions, such as incontinence and vomiting (46.8%) and the physical or emotional burden on family, friends, or caregivers (42.2%).<sup>1</sup> **These are all disability issues.**

The entirely subjective notion of suffering being proposed in the model for Victoria would allow assisted suicide for a similar set of concerns.

This set of concerns reflects the day to day realities of life for many people living with disabilities of various kinds.

If we legalise assisted suicide for incontinence, a loss of ability to engage in one's favourite hobby, a need to have others take care of your physical needs, a loss of mobility and so forth what is the take home message for those Victorians who live with these challenges every day?

Are we saying they would also be better off dead?

### STELLA YOUNG

The late Stella Young, comedian, writer and disability activist, wrote on the implications of legalising assisted suicide for people living with disabilities:

*As a disabled person, I'm accustomed to conversations about quality of life and dignity. Specifically, I'm accustomed to assuring people that my life is worth living. I'm short statured, a wheelchair user, and I frequently have bone fractures. All the visual cues that make me 'the other' are front and centre.*

*People make all sorts of assumptions about the quality of my life and my levels of independence. They're almost always wrong.*

*I've lost count of the number of times I've been told, "I just don't think I could live like you," or "I wouldn't have the courage in your situation," or, **my favourite one to overhear (and I've overheard it more than once), "You'd just bloody top yourself, wouldn't you?"**. What we as a society think we know about what it means to live as a disabled person comes from cultural representations of disability seen through a nondisabled lens. And we, as people with disability, rarely get to tell our own stories.*

*Also, social attitudes towards disabled people come from a medical profession that takes a deficit view of disability. This is my major concern with legalising assisted death; that it will give doctors more control over our lives. As a disabled person who has had a lot to do with the medical profession, I can tell you that this is the space in which I've experienced some of the very worst disability prejudice and discrimination. Doctors might know about our biology, but it doesn't mean they know about our lives.*

*Media reports on assisted dying feed these misconceptions. ABC News reported this week on the case of Barbara Harling, a Queensland woman with motor neurone disease who said that she would consider moving to Tasmania if the Voluntary Assisted Dying Bill had passed. Harling is quoted as saying: "Well, let's put it this way. I can use my left hand, my right hand is just about useless. If I can't use my left hand to wipe my bottom, then I can do nothing else for myself. That means someone has to do everything for me. I couldn't bear to live like that."*

*The thing is, a lot of people do live like that. I know many, many people who depend on personal assistants for all of their daily living tasks, some of them requiring 24 hour care. **Having to rely on someone else to wipe your bum may not be something anyone aspires to, but I'm quite sure it's never killed anyone.***

*Perhaps our discomfort with this kind of thing is why we don't hear the counter view in reports about assisted dying. Often we hear supporters of euthanasia and assisted suicide talk about wanting to avoid the pain and*

suffering that often comes with imminent death. But more often, we hear stories like Barbara Harling's, which are more about wanting to avoid a loss of autonomy and independence.<sup>2</sup>

## SCREENING FOR DEPRESSION OR COERCION

A person with a disability would be eligible under the proposed model if he or she has been diagnosed with a terminal condition.

The model would require the assessment of a psychiatrist or psychologist to screen for depression or other mental health conditions that may be affecting the person's decision making capacity. The assessing doctors do not appear to have to confirm that the request is voluntary and not the result of coercion. It is difficult to identify depression in people with disability, simply by assuming that it is normal for a person with disability to show signs of depression such as sadness and lack of hope. Doctors may also easily miss the particular vulnerability of a person living with disability to overt or subtle coercion from family or caregivers who reinforce a feeling that the person is a burden, "too much trouble", "life is too hard" and so forth.

## TERMINAL CONDITION OR DISABILITY?

The proposed model suggests making assisted suicide available to people with a 'terminal illness'; defined in the draft bill as 'less than 12 months to live.' However, the prognosis would take account of which treatments are "acceptable to the person". On this basis various conditions that are not in themselves terminal may be considered as terminal for the purpose of offering assisted suicide if the person decides to forego an effective, available treatment for whatever reason.

This approach poses a severe risk to people following an initial acquisition or diagnosis of a condition that may involve a considerable level of disability.

*Research overwhelmingly shows that people with new disabilities frequently go through initial despondency and suicidal feelings, but later adapt well and find great satisfaction in our lives. However, the adaptation usually takes considerably longer than the mere fifteen-day waiting period [generally] required by assisted suicide proposals. People with new diagnoses of terminal illness appear to go through similar stages. In that early period before one learns the truth about how good one's quality of life can be, it would be all too easy, if assisted suicide is legal, to make the final choice, one that is irrevocable.*

*Dr. Richard Radtke, a well-known retired academic oceanographer in Hawaii, provides one such example. Dr. Radtke has had a very disabling form of muscular sclerosis for over 25 years. In the period after his diagnosis, doctors often classified him as terminally ill. He experienced severe depression for two years. Had assisted suicide been legal, he acknowledges that he would have chosen it and died long ago. Today, still with an extremely limiting disability, he has retired from a successful academic career, is a happily married father, remains the president of a charitable foundation, and is grateful for the length and varied experiences of his life.*

*How many such individuals is our society prepared to sacrifice as the collateral damage from the legalization of assisted suicide?<sup>3</sup>*

## CONCLUSION

Legalising assisted suicide poses a direct threat to the lives of some people with disabilities who may be assessed as eligible to request it. Doctors are more likely to agree that they are "better off dead" and to miss signs of depression or coercion.

Legalising assisted suicide for being a burden, incontinence and loss of ability to enjoy activities trivialises issues faced daily by persons living with disability and demeans their courage in facing the challenges of life.

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<sup>1</sup> Oregon Public Health Division, *Oregon Death With Dignity Act: Data Summary 2016, Table 1. Characteristics and end-of-life care of 1,127 DWDA patients who have died from ingesting a lethal dose of medication as of January 23, 2016 [sic = 2017], by year, Oregon, 1998-2016*, p.10, <http://public.health.oregon.gov/ProviderPartnerResources/EvaluationResearch/DeathwithDignityAct/Documents/year19.pdf>

<sup>2</sup> Stella Young, "Disability a fate worse than death?", *Ramp Up*, 18 Oct 2013, <http://www.abc.net.au/rampup/articles/2013/10/18/3872088.htm>

<sup>3</sup> Marilyn Golden, *Why assisted suicide must not be legalized*, <https://dredf.org/public-policy/assisted-suicide/why-assisted-suicide-must-not-be-legalized/>

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