Voluntary
Assisted
Dying
South
Australia

VADSA Position Statement: Access to VAD for a person living with a disability

Laws around the world which allow for voluntary assisted dying commonly state that a disability alone is not a criteria for voluntary assisted dying (VAD). Our concern is that, on the contrary, having a disability may be the reason someone is denied the choice of voluntary assisted dying.

Our concern is that a person with a disability, who later acquires an illness which meets the criteria for VAD, will be refused access to VAD because of their disability. Our concern is that a person with a disability will be discriminated against in requesting VAD as a result of their disability. The complex administrative and management processes contained in the Voluntary Assisted Dying Act (2021) create substantial barriers for a person with a disability, who has now acquired a serious and incurable illness, to request VAD and successfully navigate all the VAD request steps.

As a signatory to the Convention on the Rights of Persons with Disabilities (CRPD), Australia undertakes to

> *identify and eliminate obstacles and barriers and ensure that persons with disabilities can access their environment, transportation, public facilities and services, and information and communications technologies in a similar way to other members of the community (Article 9).*

In addition, Article 4 states that

> *Countries that join in the Convention engage themselves to develop and carry out policies, laws and administrative measures for securing the rights recognized in the Convention and abolish laws, regulations, customs and practices that constitute discrimination.*

VADSA takes the view that people living with disabilities are likely to be discriminated against in the implementation of the VAD legislation. This would constitute a violation of Australia's obligations as a signatory to the CRPD. It would also be in contravention of Australia's laws on discrimination.

A concern is sometimes expressed by people opposed to VAD who also have a disability, that if VAD is made legal, their vulnerability will be exploited and the law will be used by unscrupulous family members, doctors and health professionals to end their lives; they will effectively be murdered. There is now over two decades of data from jurisdictions around the world where VAD is legal. Despite the best efforts of opponents to find evidence to the contrary, there is no evidence from any jurisdiction in the world where VAD is legal that laws are used to exploit people with disabilities. This fact was confirmed in the report of the WA Parliament Joint Committee on End of Life Choices, *My Life, My Choice* (August 2018). To be absolutely clear: there is no evidence from anywhere in the world that VAD legislation has been used to end the lives of people with disabilities against their will.

Fear of Discrimination

The Victorian Parliament *Inquiry into End of Life Choices Final Report* recommended that the key eligibility criteria for VAD be "an adult, with capacity, who is at the end of life and has a serious and incurable condition which is causing enduring and unbearable suffering" and that "it is not for others to decide what is and is not tolerable for a patient". (pp217-8)

All subsequent state and territory legislation has adopted a similar recommendation. However, the translation of that recommendation into legislation has given us major concerns that the complex and demanding VAD request and assessment process, requiring multiple consultations and requests, will have the effect of discriminating against people with a disability.

The person with the disability, once they know about VAD, will be presented with information about treatment options, palliative care, the risks of VAD; be asked many questions; be required to prove they are making the request voluntarily; be made to prove they are not suffering from depression; complete many forms; find witnesses; find VAD registered doctors and consultants; attend multiple appointments; make many phone calls. All of this while dealing with their disability and their serious and incurable illness.

To make a request for VAD, the person will need to be able to communicate convincingly with the medical people completing the assessments; the medical team will be required to state that they have no doubt that the person's request is voluntary. In a stressful situation, such as a meeting where you are requesting an assisted death, and talking to a medical specialist who you may have never met before, and who you understand has no experience with your disability, there is considerable potential that the medical person will misunderstand the person's nervousness and conclude that the request is not clear or not voluntary.

Many disabilities stem from damage to the brain. A person with a damaged brain will often struggle to communicate with other people, and in stressful situations, such as when requesting VAD, the negative effect on communication will be even more pronounced. For example, a hesitancy in response due to the person's aphasia may be misinterpreted as indecision. Aphasia is a communication difficulty, usually acquired after a stroke, where the person may struggle to find the right words and think they said one thing but may actually have used different words – there can be up to 10,000 people living with aphasia in South Australia at any one time. It is impossible to know that a person has aphasia by looking at them, and busy medical professionals do not always familiarise themselves with a person's medical history prior to a consultation. People with physical disabilities, such as an amputee, may be in a better position to be understood if they request VAD, although the logistics will still present a significant challenge, in addition to all the other challenges of daily living as an amputee.

Our consistent experience with medical authorities is that people with disabilities, especially those which stem from a damaged brain, are frequently accorded less status and respect than other patients; their views are given less credibility; and if there is difficulty in hearing or understanding the person because of their disability, their views are frequently discounted or ignored completely. There are several ways in which a disability may be misunderstood by a health professional, including a treating or consulting doctor:

1. Lack of experience with, and understanding of, the underlying disability.
2. Lack of understanding that each disability will impact each person differently; for example, MS affects each person differently and the capacity of one person with MS will be different from the capacity of another person with MS.
3. An oncologist, for example, is not a specialist in traumatic brain injury and will have limited knowledge of the impact of the TBI on the person they are treating; the oncologist could easily misunderstand the behaviour or responses of their patient with a TBI and assess them as unable to make an informed decision.

There are many situations in which a request for VAD by a person with a disability may have their request ignored or rejected.

The ABS estimates that 21% of people in Australia live with a disability. VADSA takes the position that the first step to ensuring people living with disabilities have access to VAD in a similar way to other people in the community, is to collect data on disability status during the assessment process.