

**Joint Committee on End of Life Choices
Parliament of South Australia**

**Submission from
My Body My Choice
on behalf of people with a disability**

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My Body My Choice was established five years ago by a group of people with disabilities to advocate for Voluntary Assisted Dying. We operate as a facebook group and are available to talk to people and organisations as required.

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Introduction

My Body My Choice was established to work towards the introduction of laws which would allow a person who is suffering unbearably to access voluntary assisted dying.

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). We support that policy. Our concern is that, on the contrary, having a disability may be the reason someone is denied the choice of voluntary assisted dying.

The concern of *My Body My Choice* 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 (2017) in Victoria, for example, 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 steps involved in achieving approval.

As a signatory to the Convention on the Rights of Person 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.

This submission explains our concerns about access to VAD by people with a disability and concludes that if legislation in South Australia is modelled on the Victorian Act, people 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. We propose amendments to Victoria's Voluntary Assisted Dying Act, informed by a knowledge of the impact of a disability on daily life, the purpose of the amendments being to remove that discrimination and allow people with a disability equal access to VAD.

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. We do not accept this proposition and have seen no evidence from the 17 jurisdictions around the world where VAD is legal that people with disabilities are made vulnerable to exploitative behaviour by using VAD legislation. There has been considerable effort by opponents of VAD to try and find evidence of VAD legislation being used to end the lives of people with disabilities, but no credible evidence has been found. 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 of VAD legislation being 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)

My Body My Choice supports that recommendation. However, the translation of that recommendation into legislation has given us major concerns that the large number of steps built into the legislation will have the effect of discriminating against people with a disability and result in people with a disability being deemed ineligible for VAD.

The person with the disability 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; make many phone calls. All of this while dealing with their disability and their serious and incurable illness.

To make a request for VAD under the Victorian Act, the person will need to be able to communicate convincingly with the medical people completing the assessments; the medical people will be required to state that they had no doubt about the person’s request for voluntary assisted dying. 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 your nervousness and conclude that the request is not clear.

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 actually 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 which do not have a direct impact on brain function, such as an amputee, may be in a better position to be understood and heard 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. Based on our experience and consultation with people with different disabilities, the following scenarios are presented:

- Most people with a long term disability suffer depression at some time, sometimes more severely than at other times, and the person is likely to answer that they get depressed. The same outcome is commonly reported for people with cancer: it is reasonable that a person with terminal cancer would show some level of depression, but this does not prohibit them from making an informed decision about their medical care and being able to make an informed request for VAD.
- Communication difficulties associated with the illness may mean that the medical assessment is less clear; if a doctor is unsure what the person has said, or due to their injury they have said the opposite of what they think they said, such as a person with aphasia, and the doctor chooses not to allow a support worker or family member with the person to interpret for them, then a doctor may not be prepared to approve a request for VAD. In such cases provision needs to be made for the person to nominate an advocate, friend, family member, support worker or a person who they know and trust who can 'interpret' for them during the medical consultation and be officially recognised as the interpreter – not viewed as someone pressuring the person with the disability to request VAD.
- A person with a disability who now has a terminal illness or neurological condition is likely to find the whole process of requesting VAD overwhelming; the paperwork, the many steps, finding witnesses, going to consultations; they may just give up. This is unfortunately a persistent pattern for a person with a disability which has become their learned reaction to bureaucracy; people with a disability become accustomed to service after service failing to respond appropriately and the person with the disability will again just accept they will be denied VAD as well; yet again, a disability unaware system has made it impossible for them to navigate.
- Most people with disabilities have large medical records; much information has been recorded over the years. The experience of most people with a disability is that busy health professionals rarely read these files and a quick read fails to identify the key features of the health record relevant to the consultation before them. When the consultation begins, the patient will be unsure how much to explain about their disability, whether the doctor will be offended by explaining things they may know, and the person is likely to be generally uncertain about how to proceed with the request for VAD. This uncertainty causes nervousness. If they do explain things about their disability, in their nervousness they may omit some aspects of the disability which could be critical to the doctor acknowledging their VAD request. We anticipate that a person with a disability, who is now consulting with a doctor managing their terminal illness but not experienced in their disability, is likely to be more nervous than a patient without a disability consulting with the same doctor; and the greater nervousness of the person with the disability may be interpreted by the doctor as the person not being certain about their request for VAD.
- Religious opposition of a care facility in which the person lives, such as a share home or a high care facility. Such organisations may be unwilling to support the person with a disability to make the request for VAD, to assist with making the medical appointments necessary for the VAD request to proceed, or to respond to any questions about VAD.

The situations presented above are based on the experience of people with disabilities in their day to day interaction with health professionals and the medical system. These scenarios reflect our concern that far from being vulnerable to exploitation and involuntary assisted dying if VAD is legalised in South Australia, people with disabilities are more likely to be discriminated against and refused access to voluntary assisted dying because of their disability.

The Government of Victoria Ministerial Advisory Panel on Voluntary Assisted Dying Final Report (The Panel) shares our concern that people with a disability not be denied access to VAD:

The Panel agrees that a person who meets all of the eligibility criteria and also has a disability should not be denied access to voluntary assisted dying just because they have a disability. The Panel considers this would be discriminatory. (P84)

The Panel concern, however, is limited to the communication difficulties of a person with a disability.

The Panel is also of the view that a person with a disability that affects their ability to communicate should be able to access communication assistance, including qualified interpreters, to request voluntary assisted dying and has made a recommendation in relation to this (see Recommendation 11). (p84)

A 'qualified interpreter' is usually recognised as a person with skills in a language other than English; we propose that for people with a disability, English may well be their language, but their communication difficulty related to their disability, such as aphasia or MS or Parkinson's Disease, means they are likely to need an interpreter who understands their method of speaking English. That person is likely to be a close friend or family member who has known them for a long time and understands their communication style. The term 'qualified interpreter' is unlikely to apply to a friend or family member who does not have formal 'interpreter' qualifications. In the absence of interpreting assistance from that friend or family member the person's request for VAD may be denied. *My Body My Choice* proposes that a 'disability interpreter' be available to support a person with a disability in all consultations in relation to their request for VAD; a disability interpreter would be someone well known to the person, familiar with their method of communication, knows the purpose of the consultation, and can 'interpret' at the request of the person requesting VAD.

The following case studies explain how the potential discrimination against people with a disability in requesting VAD extends beyond communication.

Case Studies

The following stories document the specific concerns of people with a disability who have thought about their own situation and what may happen if voluntary assisted dying becomes legal and they make a request for VAD. (The case studies are based on real people but names have been changed.)

Andrew

Andrew has autism and lives in a share house with three other people. Andrew has now been diagnosed with advanced pancreatic cancer. He has had one round of treatment but does not wish to undergo further treatment. He is aware his condition is terminal, and with the assistance of his support worker, has prepared a statement about how he wishes to be treated. Andrew's autism is not always obvious to everyone, they just think he's different. He is worried that his oncologist and the other members of the treating team may not understand his communication style and take him seriously; they may not respect his request to stop further treatment at some point, and potentially request VAD. He is worried that the oncologist or whoever assesses him will interpret his behaviour as meaning he is not really sure about his request; that someone is pressuring him; they might think his support worker is pressuring him to make the request. The anxiety about his future is affecting him and he has heard people talking about him being depressed. Andrew thinks that there is no point in him requesting VAD because no one will really believe him or they will misinterpret his request and it will just be a very stressful process with no good outcome. Andrew is becoming even more anxious about the suffering he will endure as his illness progresses.

Jane

Jane has a brain injury sustained after a car accident 10 years ago. She now has terminal cancer. Jane has recently moved to another accommodation centre and has had to change to a new GP because she does not have enough taxi funds to keep going to her old GP who knew her situation. The GP looks at her medications and sees that one of the drugs she takes also has an antidepressant effect.

The drug was prescribed to control some of the impacts of the brain injury, not for depression, but the GP determines that, in combination with several other behaviours resulting from the brain injury and a communication difficulty, Jane is not able to make an informed decision, is suffering from depression and is therefore ineligible for VAD. Jane's psychiatrist is not available and the psychiatrist she is referred to takes a conservative approach and supports the assessment of the GP.

John

John became a quadriplegic after a diving accident and is totally dependent on carers for all aspects of daily life. John has now been diagnosed with Huntington's Disease. His grandfather had it and his father has it. It is not known how long he will live, but once the symptoms of HD are evident, the future trajectory is a slow deterioration. John's quadriplegia means his lifestyle is fairly inactive; it means he is prone to other illnesses such as pneumonia. His HD means that he will gradually lose the ability to communicate, eat, read, participate in any social activity; his quality of life will gradually deteriorate. John will have times when he seems not to know what is happening around him, but at other times he will be very clear and discuss the current political comings and goings. At these times he has been asking why he has to stay alive. This could be interpreted as being depressed. But it is also a reasonable response to John's deteriorating medical prognosis. He is worried that if VAD becomes legal his request will be denied for the wrong reasons.

Sandra

Sandra was diagnosed with MS 15 years ago and now lives as a virtual quadriplegic. As the disease progresses, her voice has become more and more weak. Sometimes her mind wanders and it is hard to follow what she is saying, especially if she is tired. She has now been diagnosed with Type 2 diabetes. Sandra knows that due to her underlying MS she has all the risk factors which are likely to increase her risk of the diabetes becoming more and more debilitating: she is overweight because she cannot move independently, she cannot tolerate many foods and it is difficult to get a nutritionally balanced diet, she has almost no physical activity except for occasional pool therapy sessions, her sleep has been poor for decades, she lives with constant stress trying to manage carers, therapy, transport, medical appointments, daily living. So Sandra sees a bleak future. Her worst fear is that she will now have a stroke because of the diabetes and be left with no quality of life. Her communication is already difficult; if she has a stroke and is suffering, how will she be able to communicate her request for VAD if she can't put the request in her Advance Care Directive. Sandra will need someone who knows her well and can communicate on her behalf – her substitute decision maker. Sandra's fear is that her underlying MS, which has now combined with Type 2 diabetes, may well lead to a stroke, and then no-one will understand her or believe her if she determines that her suffering is unbearable and requests VAD.

Michael

Michael is an amputee who lost a leg in a motor vehicle accident when he was a child. Michael was diagnosed with Motor Neurone Disease around the age of 50. He was working full time in an Executive role in a large organisation. He soon found it impossible to continue and left the workforce. His wife and sister became his carers as the MND gradually progressed. Michael has recently moved into a nursing home as his family is unable to sustain the level of care he requires due to a deterioration in their own health.

The only available accommodation provider in the area is a religious institution whose leadership has expressed opposition to VAD. Michael is worried that if he wants to request VAD the accommodation owner will be uncooperative but he realises there is no other local choice. He thinks that VAD will now not be an option for him, unless there is a vacancy in another nursing home which is supportive of VAD and he can organise to move there. But that is likely to be very difficult and his family have worked hard to find the current place. He does not know how he would find another place to live, and he is becoming more and more incapacitated; maybe he should try and end his life

now, somehow, but he doesn't know how, and his wife or sister or children who find him would have to live with that; maybe he should try and go to a public hospital as it would be allowed there; but he wants to die in his home, not in a hospital. How could he get himself moved to a hospital anyway. If he asks about VAD where he is now while he can still communicate, will the people who manage the accommodation treat him differently and not be so helpful; will they even understand that that is what he is asking; will they pretend they don't understand. Would it be better just not to ask and put up with whatever lies ahead. Put up with the suffering, however bad it is, because trying to move or request VAD will make the environment which he calls home unbearable too. And it is easier for his wife and sister and children to visit him where he is. It's a choice between two types of discrimination. It will probably be easier just to put up with the suffering.

Julian

Julian has a severe traumatic brain injury following an accident. He has expressive and receptive aphasia as well as short term memory problems, anxiety and has been told he is likely to suffer early onset dementia. His eyesight is also deteriorating. Although he lives independently, he relies on various people for support including his ageing mother. There is a family history of neurological illness – MND and HD – and Julian is worried that if he is diagnosed with any of these, or cancer, or some other terminal illness, he will be unable to request VAD. His aphasia limits his communication and people often can't understand what he says. He knows how difficult it is to understand his aunt who has HD, so how will he be able to request VAD? He has had bad experiences with doctors since his accident and thinks they will not listen to him, will not understand what he is saying, will dismiss his request for VAD. The doctor will be too scared to approve a request from someone who is hard to understand. The only way Julian can see it working is to be able to explain all this in an Advance Care Directive. He could explain the circumstances in which he would request VAD, and then there would be no issue about doctors understanding him. He could then relax. All his worries would go away. If he gets HD or MND or some other incurable illness it is likely that his communication will be really difficult. It is already difficult. So he needs to be able to put his VAD request in an ACD. He can request 'no further treatment' so he should be able to request an end to his suffering if he has a TBI and MND or cancer. He should be able to advise the doctor to read his ACD and it will explain what he wants in future treatment. He will also need someone with him, who he has talked to before the medical consultation, and can clarify what Julian is saying if the doctor seems to be getting the wrong message. However he is worried that the doctor will think the person with him is pressuring him and won't take any notice of that person; if he has already written it in an ACD it will be clear that he has thought about all of this and is making the request voluntarily.

Sarah

Sarah had a stroke at age 53, 10 years ago. She is now in a wheelchair and is unable to speak. She lives at home with her husband and two dogs. Sarah uses a machine to communicate. She constantly says she does not wish to continue living. She knows she will not get better. She is aware of her environment and is aware that there is an organisation which can assist people to die (EXIT International). Her difficulty is that she is physically unable to acquire the equipment, set it up or use it; Sarah would need assistance to make use of the equipment and knows that this would implicate her husband. Sarah knows the word 'existential' and her husband knows when she is trying to say the word and 'interprets' for her; Sarah frequently explains that she wishes to end her suffering. Most days she sits in her chair watching TV or watching the dogs in the garden. Sarah follows the discussion about VAD and is concerned that if it is legal, no-one will believe that she is making an informed decision; they will think she is just depressed; they won't be prepared to approve her request. She has been asking her husband to find out how you prove you're not depressed.

Voluntary Assisted Dying Act (2017) Victoria

My Body My Choice has looked at the Voluntary Assisted Dying Act (2017) passed by the Parliament of Victoria. Our analysis is that the large number of steps involved in making a request for VAD will particularly discriminate against people with a disability from successfully navigating the process. We take the view that the Voluntary Assisted Dying Act (2017) is likely to have the unintended consequence of discriminating against people with disabilities. If, as we advocate, VAD is legalised in South Australia, we would advocate a number of different provisions compared with the legislation in Victoria to ensure that people with disabilities do not face yet more discrimination, this time in making an end of life choice.

The changes proposed are:

- One request for voluntary assisted dying
 - One medical assessment, confirmed by a nurse practitioner
 - One witness – the same witness used for each step where a witness is required
 - No VAD Permit
 - Seven day waiting period
 - Criteria of death being a reasonably foreseeable outcome of the condition, with no specified time until death
 - Palliative care to include voluntary assisted dying, with the palliative care team permitted to discuss it as an option
 - Person nominates self administration or doctor administration
 - Dementia to be included as a qualifying condition
 - Voluntary assisted dying able to be listed in an Advance Care Directive
1. **Number of requests:** the VAD Act requires a person who is no longer able to bear their suffering to make at least 12 requests to end their life, with waiting periods between each request. Some of the waiting periods are specified in the VAD Act, others are caused by the wait for various appointments and processes to be completed. Our reading of the VAD Act shows that there could be more than 12 discussions where the person will need to indicate that they are requesting approval for VAD. And there could be even more if the first doctor declines to be involved in managing the VAD request. The first doctor has up to seven days to respond to the patient's request to be the coordinator. If they decide not to participate, the person needs to start all over again and find another doctor and make the request again. The 'request discussions' required under Victoria's VAD Act are listed below.
 - Request 1:** an oral request in a discussion with a doctor
 - Request 2:** follow up request to doctor after consideration of request by doctor
 - Request 3:** consultation and confirmation of request to first assessing doctor
 - Request 4:** consultation and confirmation of request to second assessing doctor
 - Request 5:** written request to the first doctor after eligibility confirmed
 - Request 6:** find first witness for the initial written request, which is likely to include the need to provide information about the purpose of the form being witnessed and a request for that person to assist in the VAD request process
 - Request 7:** find second witness for the initial written request, which, again, is likely to include the need to provide information about the purpose of the form being witnessed and a request for that person to assist in the VAD request process
 - Request 8:** find a person to sign on your behalf if unable to write, again likely requiring an explanation of the purpose of the signature and a request to assist with the VAD request process (witness also required)
 - Request 9:** final request to a doctor
 - Request 10:** request a person to participate by being the contact person for disposal of drugs

Request 11: request the doctor to request a VAD permit

Request 12: request the pharmacy to dispense the medication

Our view is that this multiple number of requests is an overwhelming obstacle for someone with a serious and incurable illness causing unbearable suffering, as well as a disability.

Our view is that one request is sufficient. The initial request would set in motion a series of steps and not require the person to make continual requests. We understand that there are provisions in the VAD Act which allow for the person to withdraw from the process at any stage and we support such provisions.

2. **Number of medical assessments:** the VAD Act requires two different medical assessments to confirm the person's eligibility. The person is requesting VAD because their suffering is now unbearable – because they have a serious and incurable illness causing the suffering. This necessarily means the person has consulted with a number of doctors in the diagnosis and treatment of their condition. There would be many reports on these consultations. The purpose of the different VAD medical assessments is to confirm the person meets the eligibility criteria for VAD. These criteria are 12 months residency, confirmation of their decision making capacity, confirmation of their medical prognosis, and confirmation that the request is voluntary. The first doctor is able to confirm each of these criteria based on the medical reports already generated by the management of the patient's illness; if a doctor is unclear, further information can be requested, as occurs in relation to all other diagnoses and medical procedures.

For a person who is suffering unbearably and has a disability which makes their daily life even more difficult, it is an unfair and unwarranted burden to require an additional medical consultation, with a specialist they may have never met before, in order to prove what the consultation with the first doctor has already established, backed up by the evidence of many reports from other medical consultations concerning their incurable illness or condition. The logistics of making the specialist appointment, waiting for the appointment, getting ready for the appointment, arranging transport and a carer to accompany you to and from the appointment, telling the story again to a new person, the anxiety of hoping they will understand what you say, finding the funds for the specialist consultation, is likely to become an insurmountable barrier for a person with a disability. The whole process is overwhelming. The logistics, stress and low expectation of success in the request for VAD in Victoria, because of the requirement for a second medical assessment from a specialist in the field of the illness, is likely to discriminate against someone with a disability from making the VAD request or proceeding with the request.

Our view is that an assessment by one doctor, with appropriate written confirmation from specialists in relation to the incurable illness or condition, is sufficient to prove that the person meets the eligibility criteria; the second assessment adds nothing to the validity of the request, but is likely to create overwhelming logistical barriers for a person with a disability to proceed with their request; this would represent discrimination against a person with a disability. The discrimination may be unintentional, but is none the less discriminatory. If the Joint Committee takes the view that a formal confirmation of the medical assessment is required, then we propose that a nurse practitioner involved in the care of the person could be authorised to confirm the medical assessment. This would not require a formal medical assessment, but be a process for checking and confirming that the medical assessment is true and correct.

3. **Number of witnesses:** the VAD Act requires potentially four witnesses to be found to complete the assessment process. Two witnesses are required for the initial written request;

a third witness is required if the person cannot sign the request and someone signs on their behalf; a fourth witness is required for the paperwork associated with the appointment of a Contact Person (the Contact Person manages the return of the drugs). One witness to the signing of the request may be a family member and the others must be independent, not be beneficiaries of the estate, or employed by the person's care facility or medical team.

We believe that again identifying, contacting, discussing the request and arranging the attendance of two witnesses to a signature will be more of a barrier for someone with a disability than for other members of the community. The person may have long term mobility issues or communication difficulties which has made them socially isolated over the years, be confined to a bed due to their illness, and now be required to find up to four witnesses to a signature. The person who now has unbearable suffering, under the VAD Act, is now required to go out and find four witnesses to be part of a VAD process. This is not the same as witnesses to a wedding, where two witnesses are required; the first people approached may not wish to participate in anything to do with VAD, so the person is dissuaded from asking anyone else; many people in our society are uncomfortable talking about death and may not wish to be involved; yet a person with a disability, as well as a serious and incurable illness causing unbearable suffering, who in many cases will have poor social or communication skills, has to now approach at least three unknown people, plus a friend or family member, talk about the purpose of the witness request, probably explain why they want to request VAD, and then deal with the aftermath of a rejection.

We propose that one witness, who may be a family member, is sufficient. The role of the witness is to confirm that the person requesting VAD signed the form; the witness is not confirming the content of the request; one person can confirm that the person making the request signed the form. We propose that if further witnesses are required for the VAD request, the same (original) witness be used at each step.

4. **VAD Permit:** the VAD Act requires the issue of a VAD permit by a delegate of the Secretary of Health before VAD is approved. The delegate has the power to deny approval. A person with a disability has a lifetime of experience of intervention by bureaucracy which has overruled and intervened in various aspects of their life. For example, whether a building allows access through the front door or you have to enter through the trade entrance at the back; whether you are allowed to get on a plane; whether there is a suitable space for your wheelchair at a public event; whether a doctor will prescribe a required drug; whether Workcover will fund a prescribed drug; whether information is provided in a form which can be understood; whether arrangements and appointments are made for you without your knowledge. This is the lived experience of someone with a disability – facing discrimination every day in doing everyday things.

Knowing that yet another bureaucrat who has never met you can intervene and deny VAD, despite you having been assessed as eligible by all the people who know you and know the impact of your disability and illness, may prove an obstacle too far for a person with a disability. Based on a lifetime of experience of medical systems in particular not respecting or understanding their disability, a person with a disability may consider that the VAD system is prejudiced against their success. Just like every other system they have had to deal with in living with a disability. The expectation is that their request for VAD will not succeed and it will just use up a lot of energy – energy which is in short supply coping with a disability and now an incurable illness - so the energy is best used on day to day living needs. It is all too hard. Their suffering will then continue; the complexity of the system has effectively discriminated against the person with the disability.

The VAD Act requires VicHealth to provide a VAD permit before the prescription is written. The Secretary of the Department of Health has the power to refuse a permit, delay the

issuing of a permit, allow other people to intervene in the request for VAD. Other provisions in the VAD Act ensure the legitimacy of the VAD request. There are serious penalties for misrepresentation. Doctors are trusted to comply with their obligations under other pieces of legislation, in life and death situations; doctors are trusted to prescribe other drugs which can cause death; there is no suggestion that doctors will act dishonestly in carrying out their obligations under the VAD Act. The VAD permit is an unnecessarily bureaucratic intervention at the end of the VAD request process which will have the effect of extending the suffering of people with a serious and incurable illness, and for a person with a disability, represent the final barrier to their ability to make an informed and independent decision about their end of life choice.

5. **Waiting period:** the VAD Act has a minimum 10 day waiting period between the first written request and final request. In addition to this minimum formal waiting period there is the time between the initial oral request and the written request, the anticipated delays with seeing two doctors and waiting for an appointment with a specialist, the time taken to find witnesses and the time for the Secretary of Health to consider the VAD documentation and issue the VAD permit.

The person is likely to make the request for VAD when their suffering becomes unbearable. This may happen suddenly. Until that time the person may not see the need for VAD. For a person with a disability who has now reached the point of experiencing unbearable suffering, further delays while a range of processes take place which will then take an indeterminate amount of time extends the suffering for no apparent purpose. The person with a disability already experiences many challenges of daily living; their serious and incurable illness and associated suffering compounds that difficulty. The realisation that they may be waiting considerably longer than 10 days to be able to use the prescribed drug, and the considerable number of appointments to organise to attend, the number of forms to be completed and the need to try and keep managing the challenges of daily living associated with their disability, on top of the suffering from their illness, is likely to be seen as just too much to deal with at that time, too exhausting. Without the disability and concentrating only on managing the illness it may be possible; but managing the disability and the illness is beyond their capacity. The complex and complicated process in the Victorian VAD Act will discriminate against the person with a disability taking up the choice of VAD.

We propose that the waiting period be reduced to seven days from the time of initial request to being able to acquire the prescribed drug. We further propose that a person with a disability who makes a request for VAD be allocated a support worker to navigate, coordinate and manage the VAD application process. In Victoria, Care Navigators have been appointed to assist with information and guidance for people requesting VAD. We propose that a similar system of Care Navigators be appointed and that one of their functions be to support people with a disability navigate the VAD application process.

6. **Specified period until death:** *My Body My Choice* proposes that the criteria be changed from 'death anticipated in 6 months or 12 months for a neurodegenerative condition' to the person identifying as having reached a point where their suffering is unbearable. The compound impact on daily life of a disability, now combined with a serious illness, is difficult to forecast until it happens. A neurodegenerative disease has a different impact on each person; for example, the rate at which the symptoms escalate, the different impact on the functioning of the person such as speech or mobility. If the person already has, for example, cerebral palsy, then it is unclear how the neurodegenerative disease trajectory can be defined. It is difficult to forecast the impact of the cerebral palsy on the rate of decline associated with the more recently diagnosed neurodegenerative disease such as motor neurone disease.

What will become clear to the person who has the disability, is when the suffering of getting through each day has become unbearable. Given the combination of factors for the person with a disability, their situation could decline rapidly; because of the unknown impact of the disability on the disease trajectory, a doctor may not be able to forecast a potential time of death. A doctor may be able to confirm that death is a reasonably foreseeable outcome of the neurological condition, but be unable to provide a confirmation of the 'time to death'.

The report of the WA Parliament Joint Committee on End of Life Choices, after considering the Victorian model, recommended that the criteria be:

those who are eligible for voluntary assisted dying must be experiencing grievous and irremediable suffering related to an advanced and progressive terminal, chronic or neurodegenerative condition that cannot be alleviated in a manner acceptable to that person, where death is a reasonably foreseeable outcome of the condition. (pp212-4)

We support the recommendation of the WA Joint Committee. The criteria of 'grievous and irremediable suffering ...where death is a reasonably foreseeable outcome of the condition', rather than a specified time until likely death, would allow the person with a disability to satisfy the VAD criteria in a respectful and compassionate context while still acknowledging the need for accountability and due process in the management of VAD.

7. **Included as part of Palliative Care:** the VAD Act makes it a crime for a doctor to talk about VAD before the patient raises the question of VAD. Many people working in palliative care view VAD as a part of palliative care; an end of life choice when symptoms are unable to be relieved by mainstream medical practice and the patient will endure unbearable suffering for the foreseeable future.

The Victorian Inquiry into End of Life Choices Final Report adopted the WHO definition of palliative care, which is

Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual. (P18)

If a person's suffering can no longer be relieved, then the palliative care service needs to include the choice to end that suffering; the palliative care team needs to be able to discuss the option of VAD as part of the package of palliative care choices available to their patient without fear of prosecution. The WA Ministerial Expert Panel on Voluntary Assisted Dying also recommended that the physician be permitted to have an open dialogue with their patient about end of life choices:

The Panel considers that voluntary assisted dying is a matter for the individual doctor and patient to discuss if they wish, in the manner most appropriate to each individual case. (Exec Summary, p5)

Given that palliative care is unable to remove all pain and other physical, psychosocial and spiritual symptoms from all people at the end of life, and much of the suffering at the end of life is unable to be treated by medical intervention, we propose that VAD be included as part of the package of options available in palliative care. This would mean that a palliative care team could include VAD as an option in the information – oral and written - provided to a patient; it would mean a doctor, nurse or social worker could discuss all end of life and treatment options with the patient; it would mean that VAD could be openly discussed as a

meaningful option when there are no further medical interventions which could relieve the suffering of the patient at the end of their life.

8. **Self administration or physician administration:** the VAD Act nominates a preference for self administration, with physician administration available only if the person cannot self administer. We propose that the person be able to nominate self administration or physician administration at the time of receiving the drug. For a person with a disability, it may be unclear at the time of the first request whether they will have the physical capacity to self administer until the time comes. Life is likely to be more complicated for a person with a disability who is now managing a serious illness as well, than it is for a person who is managing the serious illness alone but not an underlying disability. The person with a disability should not experience the additional burden of feeling they need to be able to self administer and that they could be denied a request for physician administration.
9. **Dementia and Advance Care Directives:** Dementia has traditionally been nominated as an illness which will not be eligible for VAD. People with later stage dementia are often moved to an institutional setting when they are no longer able to be cared for in the community. People with disabilities have much experience with institutions and institutional life and have expressed a strong desire to not be confined to another institution. This concern becomes stronger in the context of the difficulty of finding staff who understand their disability and will treat them with respect. The overwhelming experience of people with a disability is that they frequently encounter staff in institutions who have no experience of their disability and no understanding of how to care for them.

The fear of being admitted to an institution with both a disability and now dementia leaves many people with a disability looking for an alternative solution before they reach that stage. One of the ways in which this fear can be allayed is to allow an Advance Care Directive to include VAD as a treatment option at the end of life, and for dementia to be listed as one of the criteria for the person to nominate VAD as their end of life care choice.

Other provisions in the VAD Act: *My Body My Choice* is supportive of the establishment of a body similar to the Voluntary Assisted Dying Review Board in the VAD Act, the system for management and disposal of the drug, the training processes, and other monitoring and review processes (except the VAD permit).

Victorian and WA Parliamentary Inquiries: inclusion of people with disabilities

The 2016 *Inquiry into End of Life Choices* by the Victorian Parliament is silent on the position of people with a disability.

The Government of Victoria 2017 *Ministerial Advisory Panel on Voluntary Assisted Dying* recommended that a person with a disability not be discriminated against in their application for VAD on the basis of their disability. However, the limited attention to the nature of the potential discrimination inherent in Victoria's VAD Act, means that a person with a disability in Victoria is likely to face discrimination in applying for VAD. The extent and nature of this discrimination has been documented in this submission.

The report of the WA Parliament's 2018 *Joint Committee on End of Life Choices* addresses access to VAD in terms of the potential for people with a disability and other vulnerable groups, such as elderly people, to be coerced into VAD (pp 175-177). However, the report does not explore the potential for discrimination against people with a disability because of the difficulty of making the application and successfully meeting all obligations of the request process. The WA Parliament's

report confirms that there is no evidence from any jurisdiction around the world that vulnerable people are at risk from coercion to request VAD.

The WA Inquiry states that

7.76 Individuals must not be excluded from voluntary assisted dying solely because of disability. (p221)

There is no detail in the WA report on how the proposed VAD system will be made accessible to people with a disability. This silence indicates that while there was an intention to not discriminate against people with a disability, in developing the framework for voluntary assisted dying, the Committee did not examine the impact of the proposed system on people with a disability and did not recognise that their proposed model could discriminate against people with a disability. As described in this submission, there are numerous ways in which people with a disability can be discriminated against by a VAD system which does not specifically address the difficulties for a person with a disability to navigate the proposed system. It is essential that the lived experience of people with disabilities to participate in any proposed VAD scheme be addressed. If the needs of people with a disability to ensure their equal ability to participate are not specifically addressed it is likely that the proposed VAD system will discriminate against people with a disability. This is the likely outcome of the VAD system in Victoria, despite the ambition as stated in the Ministerial Advisory Panel report, to not discriminate against people with a disability.

Summary: A Disability Aware Voluntary Assisted Dying Framework

This submission has argued for the introduction of a disability aware voluntary assisted dying framework. This means that people with a disability would have the same access to a voluntary assisted dying process as other people in the community. *My Body My Choice* argues that many provisions of Victoria's Voluntary Assisted Dying Act (2017) discriminate against people with a disability. *My Body My Choice* has explained how this discrimination would occur and has proposed changes to remove that potential discrimination. In addition to the listed amendments to the Victorian Voluntary Assisted Dying Act (2017), *My Body My Choice* has proposed a number of additional inclusions in a voluntary assisted dying framework to ensure a more equitable access to a compassionate end of life choice. The voluntary assisted dying framework summarised below is informed by an understanding of the impact of disability on the life of a person living with a disability and the requirement to ensure any proposed VAD legislation does not discriminate against a person with a disability.

This framework is drawn from the arguments made in the body of this submission.

1. One medical assessment, confirmed by a nurse practitioner
2. One witness to the signing of the request form
3. One request
4. Provision for a disability interpreter nominated by the person with the disability, the disability interpreter being a person known to the person who can interpret their communication in all consultations and discussions in relation to a request for voluntary assisted dying
5. Care Navigators to be appointed to support a person with a disability to navigate the VAD request process
6. No VAD permit
7. Seven day waiting period
8. Criteria of 'unbearable suffering' and 'death being a reasonably foreseeable outcome of the condition', not a specified time until death, such as 6 months or 12 months
9. VAD be listed as part of the palliative care end of life care choices to be discussed between the person and the palliative care team

10. Person can nominate self administration or physician administration when receiving the drug
11. VAD to be allowed as an end of life care option in an Advance Care Directive
12. Dementia approved to be listed as an eligible condition for requesting VAD and in an Advance Care Directive

Where not specifically addressed, we support the remaining provisions in the VAD Act.

My Body My Choice urges the Joint Committee to recommend in favour of a compassionate end of life choice in South Australia through the introduction of legislation to allow voluntary assisted dying.

To ensure equal access to voluntary assisted dying by people with a disability, *My Body My Choice* urges the Joint Committee to include all 12 changes listed above in developing a voluntary assisted dying framework.

Representatives of *My Body My Choice* would be pleased to meet with the Joint Committee on End of Life Choices and discuss our submission further.

Phillip Beddall

Thomas Bunning

My Body My Choice

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