Influencing and voluntary assisted dying

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Voluntary assisted dying, euthanasia, dying with dignity, physician assisted suicide – however it is labelled – has been an issue confronting communities and governments for many years.

It is one of the more polarising of issues of our time, mostly fought at the extremes, with passion and persuasion. Yet 10 opinion polls conducted in Australia between 2007 and 2016 seemed to provide evidence that the Australian public were supportive of legislation that would provide voluntary assisted dying.

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I am not the first to say that polls are polls, and one of the key problems with polls is what question is asked of whom. But i use this to demonstrate that there is interest and probable support for this legislation.

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What I want to present today is a short history of voluntary assisted dying legislation, a brief overview of MND Victoria’s position, and the power of effective advocacy to ensure that when the bill became law people with ALS/MND were not discriminated against in either using VAD or being protected from it. I will use the term VAD for voluntary assisted dying.

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And what i won’t do is argue for or against VAD.

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The international experience is largely driven by Europe and the USA. We have all heard of Dignitas in Switzerland, and of Belgium and the Netherlands. In the USA, the Supreme

Court decided that VAD was a state issue, and 24 states are currently considering VAD legislation. This is a state by state process - something like Australia.

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Australia

- First legalised in the northern territory in 1995; and voided by the commonwealth in 1997
- Tasmania came close in November 2013, when a bill was narrowly defeated in the house of assembly by a vote of 13-12.
- In November 2016, the South Australian House of Assembly rejected a private member's bill to legalise a right to request voluntary euthanasia in circumstances where a person is in unbearable pain and suffering from a terminal illness.
- On 20 September 2017, the voluntary assisted dying bill 2017 was introduced into the Victorian parliament and passed on 29 November 2017. It will come into effect on 16 June 2019
- On 21 September 2017 a voluntary assisted dying bill 2017 was introduced into the NSW parliament, modelled on the Oregon “death with dignity” Act, developed by a cross party working group that considered 72 "substantial" submissions. The bill contained *“a raft of safeguards"* including a seven-person oversight board to review all assisted deaths. On 16 November the bill was voted down 20 votes to 19.

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MND Vic position

MND Victoria neither supports nor opposes voluntary assisted dying. It has adopted a position of studied neutrality. It has and promotes its policy that “MND Victoria supports patient’s rights in all things that are lawful”.

MND Victoria represents people living with MND in Victoria, provides services and supports, and attempts to influence policy and practices that restrict access to rights created.

A good example of our influencing is our ongoing work to ensure that people living with ALS/MND are not discriminated against under the national disability insurance scheme. A simple example – people with ALS/MND in Victoria were being contacted by phone. If they didn’t answer or respond to three calls, they were, in effect, struck off. This was despite the fact that many people with ALS/MND lose their ability to speak, hold and manipulate a telephone etc. Another was telephone interviews were undertaken, with the result that assistive technology was not included in a plan. MND Australia, supported by the state associations, is overcoming both of these activities, and others.

MND Victoria is a broad church - it has as clients and members people with a wide range of views and beliefs on many issues, especially those that confront all of us – Manchester United or Manchester City? Wales or Scotland? Roses - red or white? Chinese or Thai? for example. It is unfair and inappropriate for a service organisation, working with all people with ALS/MND in Victoria, funded mainly by donations, fundraising and government, to prosecute any one position.

And so it is with voluntary assisted dying. We neither support nor oppose. But we will fight for patient’s rights in all things that are lawful.

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The legislative process

The legislative process has been lengthy. It commenced with an assisted dying framework prepared by the legal and social issues committee of parliament, which was informed by over 1000 submissions and numerous hearings.

The ministerial advisory panel on voluntary assisted dying was created to advise government about “how a compassionate and safe legislative framework for voluntary assisted dying could be implemented”, including implementation in Victoria “to provide access to eligible people while minimising risks to potentially vulnerable people”

The panel released a discussion paper, receiving 176 submissions, and conducted 14 forums and a series of roundtable discussions with more than 300 stakeholders. An interim report summarised the consultation process in an interim report to the minister in

April 2017, with public release in May 2017. The final report was provided to the minister in July 2017. I recommend the executive summary of the report as worth reading; the full report if you have time and energy.

The bill was introduced into parliament on 20 September 2017, passed on 29 November 2017, and comes into effect on 16 June 2019

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Key issues and advocacy

I have used the headings of the final report recommendations to group these issues. For people with ALS/MND, these come down to eligibility, request and assessment, and completing the process.

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Eligibility

The discussion paper canvassed a range of issues regarding eligibility. The criteria include a requirement that a person must have “decision making capacity in relation to voluntary assisted dying”.

As we are all aware, ALS/MND has a relatively common element of frontal lobe dementia, affecting executive function and decision making. Some 60% of people with ALS/MND exhibit this and research is continuing. While there was significant discussion around psychological or psychiatric assessment to determine capacity, or if capacity was affected by depression, there was no recognition that loss of executive function may impact on decision making capacity. With the focus on psychiatric and psychological assessment, we argued that for people with frontal lobe involvement in their disease, assessment by a neuropsychologist, experienced in the disease (like ALS/MND), should determine the capacity of people with frontal lobe involvement to make decisions if requested by the coordinating practitioner.

This was accepted, with the recommendation that “a referral must be made to an **appropriate** specialist for assessment”.

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Request and assessment

The request process must be initiated by the individual and be made three times - a first request, followed by a written declaration of enduring request, and then a final request. The first and third requests can be spoken, while the second must be in writing and signed.

As we all know, the ability to speak can be one of the first impacts of ALS/MND. Speech can be failing and become unintelligible to outsiders, but remain understandable to family. We argued that alternative communication would be a way to address the loss of speech due to ALS/MND, including “interpretation” by a family member, carer or other person. We also proposed that the first and third requests could be made by asking the question and an indication of agreement or disagreement with the question should be accepted as requests. Similarly, we argued that speech generating devices such as eyegaze and synthesised speech, or a communication board, could constitute making the first and third requests.

The panel agreed that “interpreters” could be used in making the first and third requests, with “interpreters” having the widest possible meaning.

The second request must be in writing, signed and witnessed.

Again, we know that ALS/MND attacks the fine motor skills required for writing and signing, reaching a point where neither is possible. We argued that a written document could be produced for the person and, in front of witnesses, signed or a mark made indicating signature on the document. For those who have no ability to hold or move a pen, we argued that the signing could be confirmed by asking a question such as “do you want this document to be considered as signed by you”? Witnesses could certify that the person indicated their wish that the document be considered as signed by them.

The panel agreed that alternatives to writing and signing a document would be acceptable as long as they addressed the other elements of making a request.

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Completing the process

The discussion paper proposed that the person using voluntary assisted dying should self - administer the prescribed medication.

ALS/MND commonly affects swallowing and peg feeding is considered one of the key interventions to extend life expectancy. As noted above, it also affects the fine motor skills, and creates problems with self-feeding.

We argued that if a person was otherwise eligible to participate in voluntary assisted dying, they should not be discriminated against simply because they were unable to take a medication from its locked container and swallow it. We highlighted that while self-administration was a protection in the proposed legislation, people who were so physically disabled that they could not self-administer yet still wanted to use the right created by legislation to end their lives should have assistance in taking the medication. We proposed that people who were so physically disabled to not be able to self-administer should have the right to have someone administer the medication, and that the medication be in different forms so that it could be self-administered or administered by another person.

The panel agreed with this approach, and made provision for the coordinating medical practitioner to administer the medication.

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So what have we learned?

- Organisations must consider the views of their membership – we are all made up of people who hold variety of views and opinions
- Positions must reflect the community of interest – ie the opinions of all we represent

- Advocacy must be about rights created and protected
- Solutions to weaknesses must be deliverable
- We must keep membership informed and engaged

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Thank you. I am happy to respond to questions.