



PWdWA and AFDO

‘End of Life Choices’

Joint Submission

15th November 2017

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People with disabilities WA (PWdWA)

Since 1981 PWdWA has been the peak disability consumer organisation representing the rights, needs, and equity of all Western Australians with a physical, intellectual, neurological, psychosocial, or sensory disability via individual and systemic advocacy. We provide access to information, and independent individual and systemic advocacy with a focus on those who are most vulnerable.

PWdWA is run by and for people with disabilities and aims to empower the voices of all people with disabilities in Western Australia.



people with
disabilities
western
australia

Australian Federation of Disability Organisations

The Australian Federation of Disability Organisations (AFDO) is the peak organisation in the disability sector representing people with lived experience of disability. AFDO and its member organisations are run by and for people with lived experience of disability.

AFDO's mission is to champion the rights of people with disability in Australia and support them to participate fully in Australian life. AFDO has strong relationships not just with its member organisations, but across the disability sector including peaks representing service providers as well as those representing families and carers.

As a founding member of the National Disability and Carer Alliance, AFDO played a key role in the campaign for the introduction of the National Disability Insurance Scheme (NDIS). As the NDIS has moved through the trial phase and begun the transition to full scheme, AFDO and its members have continued to work constructively with the National Disability Insurance Agency (NDIA) as well as Commonwealth and State and Territory governments to provide critical feedback and address implementation issues as they arise.

AFDO's members include:

Blind Citizens Australia

Brain Injury Australia

Deaf Australia

Deafblind Australia

Autism Aspergers Advocacy Australia

Down Syndrome Australia

Physical Disability Australia

Disability Advocacy Network Australia

Disability Justice Advocacy

People with Disability WA

Disability Resources Centre

People with Disabilities ACT

Women with Disabilities Victoria

Enhanced Lifestyles

Deafness Forum of Australia



Inquiry into the need for laws in Western Australia to allow citizens to make informed decisions regarding their own end of life choices

People with Disabilities (WA) Inc. (PWdWA) and the Australian Federation of Disability Organisations (AFDO) would like to thank the Western Australian State Parliament for inviting our organisations to make a joint submission on this topic.

PWdWA is the peak disability consumer organisation representing the rights, needs and equity of all Western Australians with disabilities via individual and systemic advocacy. PWdWA is run BY and FOR people with disabilities and, as such, strives to be the voice for all people with disabilities in Western Australia.

The Australian Federation of Disability Organisations (AFDO) is the peak organisation in the national disability sector representing people with lived experience of disability. Our member organisations are run by people with lived experience of disability. AFDO is the place for organisations that represent people with disability to work together to achieve common goals.

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Introduction

PWdWA and AFDO believe that choosing to end your life in circumstances involving a terminal illness is a personal choice. Further to this PWdWA and AFDO believe that the current law may need to be changed to allow people to make this choice.

PWdWA and AFDO acknowledge the significant moral and ethical complexity that is associated with the concept of assisted dying. There are a range of views in the disability community about access to assisted dying. Particular views include a significant concern that people with disability are vulnerable in the context of a state-sponsored law that allows people to choose assisted dying in the face of unbearable suffering which some in the community may attribute living with a disability to constitute. Another fear stems from the fact that Australia is an ableist society and as such is vulnerable to subjective judgements that are often negative and limiting regarding people with disability. Finally, the experience of what happened to people with disability in Germany in the late 1930's is still fresh in the minds of people with disability. People with a disability live their lives every day having to justify themselves and are rightfully suspicious when the state is considering making a law about the right to die given that history.

In the context of assisted dying being a healthcare issue, PWdWA and AFDO would like to see a healthcare system that is more responsive to the needs of people with disability. People with disability are not afforded the same quality of healthcare as other members of the community with both subjective and structural barriers existing that limit the right of people with disability to health. This includes access to palliative care.

Taking these issues and fears into account, PWdWA and AFDO support the following principle drawn from the final report of the Victorian Ministerial Advisory Panel on Voluntary Assisted Dying, "Disability should not be the reason that people access assisted dying but nor should it be the reason that people are prevented from assisted dying."¹

This inquiry by the Western Australian State Parliament was put forward with a four-week timeframe for submissions from the public and interested and affected organisations. A four-week timeframe has been very difficult for organisations such as ourselves to comprehensively engage with our membership and the broader constituency of people with disabilities in Western Australia to have an understanding of their views on this matter. PWdWA and AFDO have appreciated the extra time to gather information, and we hope our submission is considered by the committee.

Our submission is informed by a small sample of interviews with members of PWdWA who wished to participate, a review of the submissions that are currently being used to

¹ Victorian Government "Final Report: Ministerial Advisory Panel on Voluntary Assisted Dying" 2017: Recommendation 6 "That disability does not satisfy the eligibility criteria for access to voluntary assisted dying, nor does disability exclude a person from eligibility to access voluntary assisted dying

frame legislation in Victoria, and research from overseas where legislation supporting assisted dying is in place.

What are people with disability saying about End of Life Choice making

PWdWA and AFDO wanted to ensure the voice of people who have experience with the health system as a person with a disability informed our submission. A request was put out to the PWdWA membership to be involved in interviews or a focus group. Seven people took part in phone and written interviews and answered questions related to end-of-life choices and palliative care. All respondents were people with disabilities ranging in age from their 40's to 80's, and all residents of Western Australia.

All respondents had some experience of loved ones going through palliative care, or themselves experiencing illness that led them to prepare for death. When asked directly if they agreed that a person should be able to end their life or be assisted to end their life when they choose, all but one said yes. However, when asked if people with disability were or could potentially be treated differently in a palliative care environment, all but one thought that people with disability would and are treated differently and that this was concerning. The concern was around people with disability not being included and part of the decision making about their care, and the view of a person's quality of life by health professionals.

“Many “Normal” people do not understand that a person with a severe/ moderate or intellectual disability can still have a quality life, as their perception of quality of life is compared to their normal life.”

An example was given by one of our interviewees who had previously worked as a nurse about an adult with an intellectual disability who spent a lot of time at home interacting with pet birds. He needed to come to the hospital due to heart problems from being overweight. Some of the nursing staff did not see that he had a quality of life and expressed that to other staff. However, the parents and the person themselves felt that they did have a good quality of life and wanted to do what they could to extend his life.

This issue was highlighted in research done by the University of New South Wales, which found that people with an intellectual disability were twice as likely to suffer a potentially avoidable death compared to the general population². One particular experience that made the news was highlighted by the ABC 7.30 Report. A young woman with Down syndrome had a stroke and was offered less rehabilitation and medical treatment than a person without a disability of the same age. In this particular case the doctor was quoted by the parent as saying ‘look, she has Down syndrome how hard are you going to try’.³

² Trollor J, Srasuebku P, Xu H, et al Cause of death and potentially avoidable deaths in Australian adults with intellectual disability using retrospective linked data BMJ Open 2017;7:e013489. doi: 10.1136/bmjopen-2016-013489

³ <http://www.abc.net.au/news/2017-02-08/study-finds-intellectually-disabled-two-times-preventable-death/8248772>

The responses we received did not want people with disability to be adversely affected by legislation or not have access to choices that other people have.

“I think people who the general society may consider to be ‘not enjoying’ their life due to their disability or to be a burden to others, due to severe disabilities, may not be treated appropriately for acute illnesses and therefore reach a condition where they may deteriorate and be eligible for palliation.”

The above comment highlights again the issue of people with disabilities having good access to health and choices around health that are equitable with other people in the community.

The other issue that came out strongly from our interviews was the need for access to good information about palliative care options, for all people at the end of life including the health practitioners. This was expressed as needing access to advocates who could work with the person to go through all the options and information, and ensure that any choices made were made in an informed way with access to all possible supports being provided first and foremost.

The one person who disagreed with the person being able to choose to end their life when they want to, said:

“No. I do not believe someone can decide to end their own lives if they are not terminally ill. If they wish to do this, they should be treated for depression and measures taken to improve their quality of life or the quality of life of their carers.”

This respondent was the only person whose experience did not involve relatives who have died of cancer. They also made a clear distinction between a person being able to choose to end their life, and a person being able to end their life or be assisted to end their life, when in palliative care. They supported a change in legislation to allow assisted dying in palliative care.

It is unclear just from the small sample that we have, what exactly people picture when they imagine what choosing to die looks like and when it would occur. This is especially noted in that the common perception was that people would be choosing to end their life due to a terminal illness such as cancer. This was also the case in Oregon USA where there is the “Oregon Dying with Dignity Act”:

“If the experience with the ODWDA teaches us anything, it is that a very small subset of terminally ill patients seek a lethal prescription, and an even smaller group actually utilise that option. Consequently, the impact of permitting this option has not had a profound impact on how people confront terminal illness or how most patients are cared for by physicians”.⁴

⁴ Ben A. Rich “Pathologising Suffering and the Pursuit of a Peaceful Death” Cambridge Quarterly of Healthcare Ethics (2014) Vol 23 pgs 403 - 416

Only two respondents said they had knowledge of palliative care and options such as advanced health directives. One of those was the person who did not agree with people being able end their life whenever they chose. This person understood palliative care to be when there is a clear expectation that a person will not survive and a choice has been made to keep them comfortable until death. Their view was that there needed to be more choice and involvement of family in making the decision to move to palliative care rather than adding choice to end life actively at that point.

There are some people with disabilities who have been ensuring that critical questions are asked relating to the value and quality of life of people with disabilities when it came to euthanasia and assisted dying legislation.

Western Australian activist, Samantha Connor, has written and been interviewed on this issue as it arose in South Australia and Victoria. In a blog written on the issue she tries to explain the complexity for people with disabilities:

“... the concept of 'intolerable suffering' in the legislation is flawed because half of us live in poverty, are victims of abuse, have no access to care and support - our 'intolerable suffering' often comes not from our disabilities but from external sources. We don't have time to explain the concepts of ableism and how daily discrimination impacts upon our lives and often causes our deaths. Or how we often want to die because our lives are of such poor quality - although mental health conditions are outlawed under the legislation, most of us experience poor mental health as a consequence of marginalisation. Our degenerative disabilities make us eligible for a fast path to the grave, despite the careful weasel wording in the Bill - all disabilities arise from a 'medical condition'. And they will absolutely not understand that their 'safeguards' are meaningless to us - their trusted medical professionals are often our executioners because of their perceptions of our 'quality of life'. We are switched off in hospitals every month.”⁵

Her concern and that of other disability activists are that there is not a clear understanding by those who are proposing assisted dying or euthanasia legislation of the impact on people with disability and public perception of people with disability when there is a definitive allowance of people to choose assisted dying.

In preparing this submission we also briefly spoke to Consumers of Mental Health WA to ask what their concerns would be from a mental health perspective. They commented that they had mixed feelings in that there were diverse views amongst their members, and that the issue was very complex and emotional. There were extreme concerns that the message sent by allowing people to end their life by choice undermined the work of suicide prevention. They also had similar issues of the stigma associated with having a complex psychosocial disability and what that might mean for people's understanding of the quality of life with the use of terms such as 'unbearable suffering'.

⁵ Samantha Connor, Gimped 2016 <http://gimped.blogspot.com.au/2016/10/why-we-must-not-go-gently-into-night.html>

Language

AFDO and PWD WA support the position taken by the Victorian Ministerial Advisory Panel on Voluntary Assisted Dying to use the term '*Voluntary Assisted Dying*'. The term Voluntary Assisted Dying is used instead of terms such as

- Euthanasia
- Dying with Dignity
- Assisted Suicide

Voluntary assisted dying is person-centred and makes emblematic the statement, "that this is a decision initiated by a person who is suffering and who takes responsibility for the decision".⁶ It is also clearly identified with death and dying rather than using euphemisms such as 'end of life'.

PWdWA and AFDO believe that any legislation should stay clear of using terms such as "Quality of Life" and "Unbearable Suffering".

Dutch research defines 'unbearable suffering' as "a subjective experience in which the suffering is so serious and uncontrollable that it overwhelms one's bearing capacity."⁷

According to this literature 1 in 4 end of life cancer patients experienced unbearable suffering. When broken down unbearable suffering can spread across different domains. Medical signs and symptoms included weakness, general discomfort, tiredness, pain, loss of appetite and not sleeping well. It is seen as including loss of function and impaired capacity to perform activities, feeling dependent, needing help with housekeeping, being bedridden, having trouble accepting the situation and loss of control. Other domain areas that help characterise unbearable suffering include the psycho-emotional context, the socio-environmental context and the existential context.

A person newly diagnosed with a disability can experience all of these elements. Provided with support and opportunity to participate in the community this is usually limited in time as people adapt. For some people with disability some of the physical and medical domains described above are inherent in their disability. The environmental context within which a person with disability lives can also be disabling or enabling. People with disability and their families and carers can live great lives and find quality in life in a variety of ways when there is appropriate support and enabling environments. The subjectivity of the experience of unbearable suffering makes it problematic when used in the context of assisted dying.

⁶ Victorian Government "Final Report: Ministerial Advisory Panel on Volunatry Assisted Dying" 2017

⁷ Cees DM Ruijs, AD JFM Kerkhof, Gerrit van der Wal, Bregje D Onwuteaka-Philpsen "The broad spectrum of unbearable suffering in end of life cancer studies in Dutch primary care" BMC Palliative Care 2012 Vol 11

Principles Guiding Legislation

AFDO and PWD WA support the following principles taken from the Final Report of the Victorian Ministerial Advisory Panel on Voluntary Assisted Dying⁸:

- Every human life has equal value
- A person's autonomy should be respected
- A person has the right to be supported in making properly informed decisions about their medical treatment and should be given, in a manner that they understand, information about medical treatment options, including comfort and palliative care
- Every person approaching the end of life has the right to quality care to minimise their suffering and maximise their quality of life
- The therapeutic relationship between a person and their health practitioner should, wherever possible, be supported and maintained.
- Open discussion about death and dying and people's preferences and values to be encouraged and promoted.
- Conversations about treatment and care preferences between health practitioner, a person and their family, carer's and community should be supported.
- Providing people with genuine choice must be balanced with the need to safeguard people who might be subject to abuse
- All people, including health practitioners, have the right to be shown respect for their culture, beliefs, values and personal characteristics

⁸ Victorian Government "Final Report: Ministerial Advisory Panel on Volunatry Assisted Dying" 2017

A Human Rights Framework for Voluntary Assisted Dying

AFDO and PWD WA believe that Voluntary Assisted Dying needs to be supported by a Human Rights Framework.

“Promoting individual autonomy and providing appropriate safeguards are critical, and neither aim is paramount. Instead, they must be balanced. An appropriate balance should not only recognise the importance of these aims separately but also the role they play in promoting each other”⁹

The Victorian Ministerial Advisory Panel identified the following seven core rights as particularly relevant to Voluntary Assisted Dying. These include:

- The right to recognition and equality before the law
- The right to life
- The right to protection from torture and cruel, inhuman and degrading treatment
- The right to privacy and reputation
- The right to freedom of thought, conscience, religion and belief
- The right to protection of the best interests of the child
- The right to liberty and security of the person

In relation to the Article 12 of the Convention on the Rights of Person with Disability The right to recognition and equality before the law” AFDO and PWD WA support the position that people with disability should have access to Voluntary Assisted Dying

⁹ Victorian Government “Final Report: Ministerial Advisory Panel on Voluntary Assisted Dying” 2017

Overseas Evidence in relation to vulnerable groups

In Oregon, there is no recorded data of people participating in assisted dying on the basis of disability alone. The situation in the Netherlands is different where assisted dying for disability alone is not illegal. In principle, a person who faces unbearable suffering in his or her own view and who has been offered all forms of treatment with no improvement may request assistance in dying. “In 2005, less than 10 people in approximately 2400 cases were assisted to die or 0.2% of the group of people accessing assisted dying”¹⁰.

There is no evidence to suggest, from either Oregon or the Netherlands data, that people with disabilities are at heightened risk of assisted dying. Vulnerable groups generally including women, ethnic minorities, people from lower socio-economic circumstances, children, people with a psychiatric disability or dementia were not found to be at any heightened risk of assisted dying. People with psychiatric disability (mainly depression) constituted 20% of referrals to the Netherlands assisted dying process, but none progressed. Likewise, in Oregon, none of the 292 people who have accessed assisted dying did so due to mental illness.

80% of deaths from assisted dying legislation in both Oregon in the United States of America and the Netherlands result from a terminal diagnosis associated with cancer. The second most statistically significant group were people with a terminal diagnosis associated with ALS (Amyotrophic Sclerosis)

¹⁰ Margaret P Battin, Agnes van der Heide, Linda Ganzini, Gerrit van der Wal, Bregje D Onwuteaka-Philipsen “Legal physician-assisted dying in Oregon and the Netherlands: evidence concerning the impact on patients in “vulnerable” groups” *Law Ethics and Medicine* 2007; Vol 33 pgs 591 - 597

People with Intellectual Disabilities and End of Life Decision Making

The process of End of Life decision making for people with intellectual disability could be improved by, “defining clear roles and responsibilities of all participants involved. If possible people with IDs themselves should be involved in the decision-making process. Knowledge of their needs and preferences, quality of life and life stories could improve the decisions.”¹¹

The types of support to people with intellectual disabilities who are participating in End-of-Life decision making and patient representatives who are supporting them includes:

- Being involved in the decision-making
- Be empathic
- Provide time to think and deliberate
- Know the family and the different roles in the family
- Positively value the role of patient representatives
- Provide reassurance

¹¹ Annemieke MA Wagemans, Henry MJ Van Schroyen Lantman-de Valk, Ireen M Proot, Job Metsemakers, Irene Tuffrey-Wijne, Leopold MG Curfs “End-of-Life Decisions for people with intellectual disabilities, an interview study with patient representatives” *Palliative Medicine* Vol 27 (8) pgs 765 - 771

Assessing Decision Making Capacity at End of Life

Article 12 (1) and (2) of the Convention on the Rights of Persons with Disabilities state¹²:

1. States Parties reaffirm that persons with disabilities have the right to recognition everywhere as persons before the law.
2. States Parties shall recognize that persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life.

Decision-making capacity under domestic law is a static assessment whereby you either have the capacity or you lack capacity. In practice, however, capacity is fluid. People who lack capacity one day may exhibit capacity the next day. Capacity can be affected by urinary tract infections but restored once the infection is healed. People may have capacity in the morning but lack capacity as they tire toward the end of the day.

“Up to 50% of people will not be in a position to make their own decisions as they near the time of their death.”¹³

People with a terminal illness are responsible for making important healthcare decisions, some of them controversial or at odds with family members or the medical system, even after their disease has advanced beyond cure. To be autonomous in decision making, particularly during end of life requires people to continue to have the capacity to do so.

Clinicians are largely responsible for making decisions about whether a person is competent and use the frequently applied measure called Mini-Mental State Examination (MMSE). Is this a reliable indicator of capacity generally, or for people with disability specifically? Most studies conclude that the MMSE was at best a modest predictor of decision-making capacity, “Thus, critics have argued that cognitive measures such as the Mini-Mental State Examination (MMSE) are not adequate to evaluate the patient’s specific capacities to understand, appreciate and reason about information related to a particular treatment.”¹⁴

¹² Convention on the Rights of Persons with Disabilities Article 12

<https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html>

¹³ National Health and Hospitals Reform Commission (2009): A Healthier Future For All Australians – Interim Report December 2008. Commonwealth of Australia 2009 (pg188)

[www.nhhrc.org.au/internet/nhhrc/publishing.nsf/content/BA7D3EF4EC7A1F2BCA25755B001817EC/\\$File/NHHRC.pdf](http://www.nhhrc.org.au/internet/nhhrc/publishing.nsf/content/BA7D3EF4EC7A1F2BCA25755B001817EC/$File/NHHRC.pdf)

¹⁴ Elissa Kolva, M.A., Barry Rosenfeld Ph.D., Robert Brescia, M.D., Christopher Comfort, M.D. “Assessing decision-making capacity at end of life” *General Hospital Psychiatry* Vol 36 (2014) 392 - 397

Advanced Care Planning

Advanced care planning enables a person to plan for their future medical treatment and other care for that time when the person may lack the capacity to do so or be unable to communicate. Advance Care Planning highlights a number of key processes including:

- Providing appropriate information about options
- Consulting with the person, family members and healthcare providers
- Understanding available future options and choices
- Recording and communicating a person's goals, values and wishes
- Appointing a substitute decision maker if required

A fear that was shared to the Victorian consultation of Voluntary Assisted Dying was the future loss of decision-making capacity. Criteria regarding access to assisted dying forming part of an advance care directive differs in international jurisdictions and centres on whether a person is conscious. Other jurisdictions do not make any reference to access to assisted dying via an advance care directive.

PWdWA and AFDO support the conclusion offered by the Victorian Ministerial Advisory Panel that “there is a fundamental difference between refusing lifesaving medical treatment in an advance care directive and requesting voluntary assisted dying”.¹⁵ PWdWA and AFDO believe that an advance care directive should not be used to request voluntary assisted dying.

¹⁵ Victorian Government “Final Report: Ministerial Advisory Panel on Volunatry Assisted Dying” 2017

Equitable Access to Healthcare for People with Disabilities

“The [National People with Disability and Carers Council's Shut Out report in 2009](#) also gave a sobering account of the exclusion of disabled people from primary and tertiary healthcare including comorbidity arising from a lack of access to yearly checkups and health screenings.”¹⁶

A range of bureaucratic and practice barriers exist in the healthcare system that limits the rights of people with disabilities to access end of life support resulting in suboptimal care. This continues to the present day and in the face of the implementation of the National Disability Insurance Scheme has been sharpened and highlighted. The 2011 Productivity Report which heralded the birth of the NDIS failed to review ageing or end of life issues for people with disabilities and it is uncertain how the NDIS intends on addressing existing concerns about access to healthcare for people with disability, “There is confusion regarding the healthcare support roles expected of specialist disability services under the NDIS and particularly in relation to generalist care that traditionally occurs through mainstream health providers (Wark, Hussain & Edwards 2015)”.¹⁷

In 2015 the New South Wales Ombudsman specifically noted in a report regarding reviewable deaths of people with intellectual disabilities the need for ongoing need for appropriate support and care models during the end of life.

It is clear that people with disability are not provided with equitable access to the healthcare system and that as a result of this experience poor health outcomes included shortened lifespans. A number of disability advocates would like to see improved access, and outcomes from the healthcare system before any talk of access to assisted dying occurs.

“The reality is that people like me *don't get choices* in too many areas of our lives. That includes a preventative and tertiary health system that is staggeringly unfriendly to us, even if people with disability and/or chronic conditions should be their best customers.”¹⁸

PWdWA and AFDO support the call for an improved healthcare system that provides for equitable access for people with disability. PWdWA and AFDO believe that people with

¹⁶ Craig Wallace “Euthanasia a choice for people with disability? It's a threat to our lives” September 27 2017 The Guardian online <https://www.theguardian.com/commentisfree/2017/sep/27/euthanasia-a-choice-for-people-with-disability-its-a-threat-to-our-lives>

¹⁷ Stuart Wark, Rafat Hussain, Arne Muller, Peta Ryan, Trevor Parmenter “Challenges in providing end of life care for people with intellectual disability: Health Services Access” Journal of Applied Intellectual Disability 2017 Vol 30 pgs 1151 - 1159

¹⁸ Craig Wallace “Euthanasia a choice for people with disability? It's a threat to our lives” September 27 2017 The Guardian online <https://www.theguardian.com/commentisfree/2017/sep/27/euthanasia-a-choice-for-people-with-disability-its-a-threat-to-our-lives>

disability are worth investing in and as citizens of Australia have the right to quality healthcare outcomes.

However, PWdWA and AFDO also believe that the call for an equitable healthcare system for people with disability is a different discussion to the discussion that is the focus of this Submission. The call for an improved healthcare system more responsive to the needs of people with disability and the call for assisted dying are not mutually exclusive. People with disability want both, “People with disability in Tasmania have clearly asserted that they want to participate in all aspects of their lives, including their end of life care. They can (and should) be directing their supports based on their informed decisions in a manner that acknowledges and respects their wishes for where and how they want to be supported until the end of their lives.”¹⁹

¹⁹ Liviende Veranto “Quality End of Life Care for People with Disability, A Tasmania Perspective” March 2016

Palliative Care

“Palliative Approach – aims to improve a resident’s quality of life through early identification, assessment and treatment of pain, physical, cultural, psychological, social and spiritual needs. A Palliative Approach is not confined to the end stages of illness; it provides a focus on providing comfort and actively reducing a resident’s symptoms and distress, and all healthcare providers can incorporate the palliative approach into their practice.”²⁰

Equitable access to palliative care as with access to other parts of the healthcare system is a mixed bag for people with disabilities. There are a range of barriers to people with disabilities experiencing equitable outcomes from the palliative care system. In 2008, Tuffey-Winje questioned specialist palliative care professionals regarding the top five issues that can act as barriers to providing palliative care to people with intellectual disability.²¹ These included:

1. The person with an intellectual disability not being able to understand their illness
2. Communication with the person with an intellectual disability
3. Difficulty in assessing pain
4. Difficulties in assessing other symptoms
5. Length of time it took to gain the trust of the person with an intellectual disability

When asked what might improve the care provided, specialist palliative care professionals identified the following that would improve the quality of the care provided:

- The need for training on intellectual disability
- A disability link in the palliative care service
- Access to background information on the person with an intellectual disability
- Resources to help provide support
- Contact details of local disability providers

PWdWA and AFDO support further training and connection by palliative care specialists to disability advocacy and disability support providers. The need for this connection also came up clearly from respondents to our interview. Having an independent advocate and other people around who can support a person to understand all of the different options available to book to them is extremely important.

²⁰ Victorian Government Department of Human Services “Disability Residential Services Palliative Care Guide: End-of-Life Care for Residents of Disability Residential Services

²¹ Tuffey-Winje, I et al (2008) “Palliative Care provision for people with intellectual disabilities: a questionnaire survey of specialist palliative care professionals” *Palliative Medicine* Vol 22 pgs 281 - 290

Conclusion

The interviews that we undertook and the information that we have gained from activists in the area show that opinions are divided, however many of the relevant concerns are about adequate support for people with disability to have equitable opportunities in life and support to live good lives. There are still many issues that require addressing under the National Disability Strategy in terms of access to quality health care and equitable access to supports in the community that are not the purview of this enquiry but nonetheless make a difference to the lives of people with disability.

PWdWA and AFDO see that this is an issue of individual choice and control, but the impact on the messages to society about people with disabilities and quality of life is bigger than any one individual's choice.

PWdWA and AFDO recommend an approach with appropriate safeguards and a focus on people with a terminal illness. The language that any legislation or discussion uses often frames the way people view this issue. The panel looking into this issue must be mindful of how language is used and how language that is subjective interacts with the community and personal views of disability, mental health, suicide, and end of life choices.

PWdWA and AFDO suggest that safeguards and principles around assisted dying are developed with representatives of people with disability. People with disability and their representative organisations also need to be involved in improving palliative care treatments. The systems in place in Western Australia are different to those of Victoria and so must be put in the context of Western Australia. However, there is much to learn from looking at how this debate has progressed in Victoria and the engagement of people with disability through the Victorian Ministerial Advisory Panel on Voluntary Assisted Dying.

This Inquiry has provided a starting point for some of these conversations in Western Australia and PWdWA and AFDO request that we continue to be included in any further discussions or consideration.

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