

**Written Submission on Inquiry into aged  
care, end-of-life, palliative care and  
voluntary assisted dying**

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Submitted To:  
Health, Communities, Disability Services and  
Domestic and Family Violence Prevention  
Committee, Queensland Parliament

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## About Queenslanders with Disability Network (QDN)

QDN is an organisation of, for, and with people with disability and the organisation's motto is "nothing about us without us." QDN operates a state-wide network of members who provide information, feedback and views from a consumer perspective to inform systemic policy feedback to Government and peak bodies. QDN also provides information and referral support to people with disability.

QDN has over 1500 members and supporters across Queensland who provide QDN with the perspectives of people with disability.

## Introduction

QDN welcomes the opportunity to make a submission to the Inquiry into aged care, palliative care and end-of-life care and voluntary assisted dying (the Inquiry). Additional to this submission, QDN has been invited by the Council on The Ageing Queensland (COTAQ) and Health Consumers Queensland (HCQ) to lead some Kitchen Table Discussions on this Inquiry with our Local Support Groups<sup>1</sup>. The opinions of people with disability on the issues raised in the Discussion Paper are diverse and reflective of the general community and need to be included and heard in the consultation process.

Generally, however, QDN members have provided feedback that there needs to be:

- More accessible information available about end of life care, palliative care and voluntary assisted dying.
- Opportunities for people with disability to receive and digest information, ask questions and have the space to come to informed decisions about voluntary assisted dying
- More targeted consultations delivered with a degree of sensitivity and understanding of how the issue of voluntary assisted dying impacts on people with disability

QDN's response will begin by outlining a disability context to aged care, end of life care, palliative care and voluntary assisted dying. QDN's response will then go on to address specific issues in the discussion paper from the perspective of people with disability. It is important for government and community to understand this perspective so we can all engage in a meaningful dialogue about this important issue. It is vital that people with disability are adequately consulted in the Inquiry and have the time to contribute to the discussion and give considered feedback. QDN's response is reflective of the views and feedback from our members.

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<sup>1</sup> QDN has 21 Local Support Groups around the State made up of people with disability who come together to discuss issues of shared and local importance in their communities. For further information see:

<https://qdn.org.au/our-work/local-support-groups/>

## **A disability context to aged care, end of life care, palliative care and voluntary assisted dying**

The issues outlined in this Inquiry are complex and can be subject to mixed public opinion among everyday Australians. For people with disability there are further layers of complexity to these issues. People with disability are quite often not consulted or considered a legitimate stakeholder in these issues and have limited choices regarding their everyday care, the settings in which they reside and receive care and support, their health and well-being, and access to quality treatment options, and support and information they can understand.

People with disability who are from Aboriginal and Torres Strait Islander backgrounds, culturally and linguistically diverse backgrounds, women, identify as LGBTIQ+ and who have intellectual and psycho-social disability face additional barriers and need targeted strategies concerning their living arrangements, support in understanding these issues, making informed decisions and contributing their feedback.

People with disability often have a wider range of stakeholders such as family, friends, partners, support workers, allied health, medical professionals, informal and formal advocates, including public advocates and adult guardians that they are reliant on for support, or legally required to get permission from, and who need to be consulted on issues concerning their health care and end of life decisions. Conversely, some people with disability have very few unpaid people in their lives. Some people with disability by definition of their impairment, lack capacity to make decisions without the support of others. However, it is critical that all people with disability, including those with impaired decision-making be supported. People with disability need accessible information and adequate support to understand the full range of choices and complex decisions involved in these matters.

Generally, in society people with disability experience lower status than those without disability and are more likely to live in poverty, experience poorer health outcomes, have difficulties accessing and affording appropriate housing and healthcare and are under-represented in open employment<sup>2</sup>. People with disability may be subjected to additional attitudinal barriers, commonly held assumptions and myths about disability by professionals in charge of their care and treatment in health settings. These biases can often go unchecked and can result in poor health outcomes and limited treatment options being offered to people with disability. The bias that is held about the lives of

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<sup>2</sup> For more information, see the report “Shut out, The experience of people with disabilities and their families in Australia”: <https://www.dss.gov.au/our-responsibilities/disability-and-carers/publications-articles/policy-research/shut-out-the-experience-of-people-with-disabilities-and-their-families-in-australia?HTML>

QDN believes it is critical that work is undertaken in the training of doctors, nurses and health professionals, particularly relating to disability-specific curriculum development. This could include:

- The development, piloting and evaluation of model curriculum enhancements to include core intellectual disability, physical and mental health content, in university medical and nursing schools. People with disability need to be involved in the design, implementation, teaching and evaluation of these curriculum enhancements;
- Funding education programs and initiatives in Primary Health Networks and universities, to increase capacity of General Practitioners (GPs) and other allied health professionals to better meet the needs of people with disability; and
- Funding a specific program in Primary Health Networks to enhance the capacity of GPs and other primary health services to respond to the needs of people with intellectual disability and to link them to appropriate healthcare;

Furthermore, people with disability can be confronted with messages and images in the media, online and in popular culture about disability that reinforce feelings of difference, that they are not 'beautiful', that they are 'a burden' on loved ones and 'the system' and that their lives are 'worth less' than people without disability. *Million Dollar Baby* (2004) and *Me Before You* (2016) are examples of films in recent times that explore end of life issues through the lens of coming to terms with newly-acquired disabilities. In both films, each lead character, one a working-class up-and-coming female boxer and the other a young businessman from a wealthy family, decide to end their lives upon acquiring spinal injuries resulting in permanent disability. At the time of their releases, both movies received a public outcry of criticism from disability activists about the portrayal of people with disability in major feature films<sup>34</sup>.

As one activist put it (speaking of *Me Before You*), "... as a wheelchair user myself I find [the film] to be saddening, because it's portraying this idea that people with disabilities lives are not worth living and that we're better off dead than disabled".

In the broader context of health, of *Million Dollar Baby*, the Chicago Tribune points out: "It is true that "Million Dollar Baby" is only a film, but when it comes time for many people to **make health decisions about themselves or a loved one's future**, what experience or knowledge will they fall back on? Few people have personal experience with severe disabilities, and few will take the time to find out about what life is like living with deafness, blindness or disability. No, most people will fall back on what they know -- which is what they have garnered from novels, plays, films and television shows".

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<sup>3</sup> For more information on criticism of the portrayal of disability in *Million Dollar Baby* see: <https://www.chicagotribune.com/news/ct-xpm-2005-02-02-0502020017-story.html>

<sup>4</sup> For more information on criticism of the portrayal of disability in *Me Before You* see: <https://www.abc.net.au/news/2016-06-17/me-before-you-criticised-by-disabled-community/7519648>

With few positive messages about disability in the public domain, one cannot underestimate the effect these influences have in shaping the self-worth of a person with disability and more broadly, society's views and helping to create a dialogue about what is valued and what is not. Therefore, it is important to consider the context of disability this Inquiry.

## Aged Care

QDN notes that disability is acknowledged in the Discussion Paper but only in the context of people who acquire disabilities as a condition of ageing. QDN is aware there are many people with disability currently living in aged care facilities as a result of acquiring a disability or because their support needs have increased as a result of a degenerative disability and they are unable to continue being supported by their loved ones or their support packages are not adequate to cover the costs of their care. This results in many people being inappropriately placed in long stay wards in hospitals or prematurely entering aged care facilities.

It is widely acknowledged that living in residential aged care can be detrimental for a younger person with disability. It can result in reducing their independence, limiting their ability to reach their full potential and it can be socially isolating – 83% of younger people in residential aged care rarely or never go outside and around 13% never go outside<sup>5</sup>.

The issue of younger people with disability living in aged care facilities occurs when people's needs are not met in the disability housing and health systems. The National Disability Insurance Scheme (NDIS) is going some way to addressing these issues but lack of affordable, accessible and safe housing is the other big issue.

QDN believes addressing the following issues will help to solve the complex issue of younger people with disability residing in aged care and supports recent announcements in relation to Supported Disability Accommodation (SDA) and improved pathways to attempt to address these:

- **Housing:** the range and scale of accessible housing needs to be increased with specific targeted strategies for young people with disability to access the housing options they need in order to exit aged care. QDN's Housing Position Paper Going for Gold: Accessible, Affordable Housing Now<sup>6</sup> contains four key principles, 11 major recommendations and a number of strategic actions that can be taken now by Government, private and community sector stakeholders to address this fundamental human need and human right - to have a place to call home.

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<sup>5</sup> For more information see: <https://www.agedcareguide.com.au/talking-aged-care/younger-people-with-disability-in-aged-care>

<sup>6</sup> For more information, see: <https://qdn.org.au/wp-content/uploads/2018/06/QDN-Going-for-gold-position-paper.pdf>

- **NDIS:** younger people with disability living in nursing homes, or at risk of entering one, need to have access to achieving effective NDIS plans with the funding they need to live as independently as possible in the community. This includes access to targeted information about what the NDIS is and what is in it for them, access to support services that will assist them to meet eligibility and access requirements, assist them in the pre-planning and planning stages and provide access to effective supports coordination services to enable a successful transition to the community.
- **Improved Pathways:** improving the interface between the NDIS, health and aged care is critical to prevent young people being discharged from hospitals into nursing homes.
- **Community and Primary Health:** it is acknowledged that people with disability and complex support needs often live within a narrow margin of health. Access to targeted, inclusive and proactive health services that sustain community living for young people with disability must be increased.

QDN intends to make a submission to the Aged Care Royal Commission and encourages the Health, Communities, Disability Services and Domestic and Family Violence Prevention Committee to maintain contact, work collaboratively and where appropriate share information, strategies and findings from this Inquiry with Royal Commission staff.

## End of Life and Palliative Care

QDN believes people with disability have the right to access the full range and highest available standards of end of life and palliative care services offered to all people in Queensland. People with disability should be consulted as much as possible about the planning and delivery of services provided to them, including accessible information on all available treatment options, medications and other approaches used in their care. People with disability, like other patients, have the right at any time throughout their treatment to seek further information, cease a treatment option, seek second opinions by qualified medical professionals, explore and have reasonable access to alternative therapies and treatments and give their own opinions about their healthcare in a Palliative Care environment.

People with disability must continue to have access to any disability related aids and equipment during their care. This may also include acknowledging the role of assistance animals and/ or pets, and consulting the people closest to them (including family members, partners and support workers) about what their personal care needs are and allowing those people to provide aspects of their personal care if it is the expressed wish of the person.

In preparing this submission, QDN members have also reflected on the importance of palliative care staff acknowledging the needs and wishes of people with disability who may be family members, partners, friends, supporters and informal carers of people using palliative care services.

## Voluntary Assisted Dying

QDN supports an open, transparent discussion and development of a legal mechanism for Voluntary Assisted Dying (VAD) that is reflective of contemporary societal views on choice concerning end of life and which has at its core best practices in healthcare within an ethical and legal framework. Given concerns expressed earlier in QDN's submission about the intrinsic value of the lives of people with disability and the messages people with disability receive about their worth, QDN believes special provisions need to exist which include safeguards for vulnerable people.

QDN strongly encourages Queensland to develop a set of core values for end of life care to guide practice similar to Victoria's<sup>7</sup> which include:

- Every human life has value – every individual has inherent value
- Open discussion about death and dying should be encouraged and promoted
- People should be able to make informed choices about the end of their life
- End of life care should be person-centred
- End of life care should address the needs of families and carers
- Pain and suffering should be alleviated for those who are unwell
- Palliative care is an invaluable, life-enhancing part of end of life care
- High quality end of life care should be available to all people in all settings
- Each person should be entitled to core rights in end of life care
- Vulnerable people should be supported and protected - Safeguards need to be in place to ensure that vulnerable people are not pressured or coerced into making decisions that they do not want to.
- The law should be coherent and transparent - Health practitioners and patients should be fully aware of their legal rights and responsibilities in end of life care.
- The law should be followed and enforced - The purpose of end of life legislation should be to provide for end of life choices for patients and protection for doctors. Breaches of laws should be penalised appropriately.

QDN believes safeguards are required to protect vulnerable people. For instance, according to Victoria's Voluntary Assisted Dying Bill:

A person is not eligible for access to voluntary assisted dying if they have a mental illness only, or if they have a disability only. Those with a mental illness and/or a

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<sup>7</sup> See:

<https://www2.health.vic.gov.au/.../%7BB5260B7D-C28B-4772-AFF0-871CFEA23ED...>



disability, however, are not precluded from taking part if they also fulfil the eligibility criteria<sup>8</sup> (cl 9(2) and (3))

Other safeguards could include but are not limited to:

- Only allowing VAD to be made available to terminally ill people for whom there is no hope of recovery (in line with Victoria's Bill)
- Providing mediation or assisted decision-making processes for people who are vulnerable
- Providing targeted user friendly information to vulnerable people in a variety of formats that outlines options and treatment plans in relation to end of life treatment
- Providing counselling services delivered by professionals who are trained in the specific needs of vulnerable populations
- Providing peer support and safe places, and increased time for people to think through their options and come to informed decisions
- Seeking the views of family members, loved ones, informal and formal decision-makers, advocates and other professionals in the person's life and encouraging them to form a circle of support around the person.

For extremely vulnerable people, there may be advantages to separating the process out to be independent of the medical system (or a requirement to document the steps taken to demonstrate independence) to avoid the risk or the perception of coercion.

QDN recommends the Committee conduct specific targeted consultation with people with intellectual and psycho-social disability and their supporters to explore how their specific needs and circumstances can be taken into consideration in relation to VAD.

## Conclusion

QDN is pleased to provide a disability perspective to the issues of aged care, end of life care, palliative care and voluntary assisted dying. Further targeted consultation, information and support alongside strategies to safeguard vulnerable people is required for people with disability to come to an informed decision on these matters. QDN looks forward to further engagement in the process of developing legislation on voluntary assisted dying.

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<sup>8</sup> Victoria's Voluntary Assisted Dying Bill 2017 eligibility: 18 years and over, permanent resident of Victoria, have decision-making capacity; diagnosed with a disease, illness or medical condition that is incurable, advanced, progressive and will cause death, and is expected to cause death within less than 12 months; and be experiencing suffering that cannot be relived in a manner that the person considers tolerable  
<https://www.parliament.vic.gov.au/publications/research-papers/download/36-research-papers/13834-voluntary-assisted-dying-bill-2017>