The Public Advocate
Influencing change to transform lives

2 July 2021

Health and Environment Committee
Parliament House
George Street
Brisbane QLD 4000

Via email to: hec@parliament.qld.gov.au

Dear Health and Environment Committee members,

Thank you for the opportunity to make a submission in response to the Inquiry into the *Voluntary Assisted Dying Bill 2021*.

The position of Public Advocate is established under the *Guardianship and Administration Act 2000* (Qld). Broadly speaking, the role of the Public Advocate is to promote and protect the rights and autonomy of Queensland adults with impaired decision-making capacity, and their participation in all aspects of community life. More specifically, the Public Advocate undertakes systemic advocacy to:

- promote and protect the rights of adults with impaired decision-making capacity for a matter;
- promote the protection of them from neglect, exploitation or abuse;
- encourage the development of programs to help them reach the greatest practicable degree of autonomy;
- promote the provision of services and facilities for them; and
- monitor and review the delivery of services and facilities to them.[1]

In line with my role, this submission concentrates on issues affecting people with impaired decision-making capacity.

As you may be aware, I provided a submission to the Queensland Law Reform Commission's *Inquiry into a legal framework for voluntary assisted dying*. A copy of that submission is enclosed for your reference.

I support the Bill's approach requiring that a person must have decision-making capacity throughout the voluntary assisted dying (VAD) process. I further support the Bill's clear approach that the VAD process is not applicable to the *Guardianship and Administration Act* or the *Powers of Attorney Act*, meaning that the VAD process will not be open to people through a substitute decision-maker or other enduring arrangements.

Further, as noted in my submission to the QLRC's Inquiry, I support the approach in the Bill in relation to the adoption of guiding principles, the definition of capacity, the ability of those diagnosed with a disability or mental illness (should they have capacity to make such decisions), and the involvement of QCAT to review administrative decisions regarding the VAD process.

Issue of palliative care
We cannot have a community discussion about VAD without considering the issue of palliative care. As a community we must commit to the availability of high-quality palliative care for all

[1] *Guardianship and Administration Act 2000* (Qld) s 209.

Queenslanders. In a first-world country we should all be entitled to 'die a good death' and this cannot occur unless people can easily access the specialist pain relief and sedation provided by palliative care that is necessary to support this outcome.

As already noted in the various submissions and recommendations of the earlier Parliamentary inquiry into aged care, end-of-life and palliative care and voluntary assisted dying,[2] there are numerous problems with the availability and quality of palliative care in Queensland. The inquiry highlighted an inconsistent, fragmented system that requires significantly better resourcing, accountability, transparency and accessibility for all Queenslanders.

It was also clear from many of the submissions to the inquiry that some members of the community were seeking VAD as an option because of the limited availability of high-quality palliative care having seen family members die in pain and distress.

I cannot emphasise enough the need for better palliative care services to be available in Queensland alongside the availability of VAD. There will be many people in our community who will not be eligible for VAD, or will not chose that path. For those, and in particular for people with impaired decision-making capacity – people with intellectual disability, acquired brain injury or dementia – we must have an appropriate model of quality palliative care that is widely available and accessible to support them to have the best death possible.

I am concerned that there appears to be some debate about whether the provision of palliative care is a Commonwealth or State responsibility, especially for aged care residents. This issue needs to be resolved as a matter of urgency for the sake of the Queensland community. We need to commit to the provision of quality palliative care to all Queenslanders at the end of life.

I would urge the members of the Committee, in addition to their commentary on the Bill, to recommend that the Queensland Government introduce a palliative care package for the whole State that will address these issues of quality, availability and access, to complement the introduction of the VAD legislation.

VAD should never be viewed as an alternative to high-quality palliative care. Quality palliative care and VAD should exist as options in a larger end-of-life package of supports for Queenslanders. The choice of a good death supported with properly resourced, accessible, high-quality palliative care should be just as available to every Queenslander as the government is proposing VAD should be.

Thank you for the opportunity to make a submission in relation to the very important considerations and issues associated with voluntary assisted dying legislation for Queensland.

Yours sincerely,

Mary Burgess
Public Advocate

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[2] Health, Communities, Disability Services and Domestic and Family Violence Prevention Committee, *Aged care, end-of-life care and palliative care* (Report No. 33, March 2020)

The Public Advocate
Influencing change to transform lives

26 November 2020

Mrs Jenny Manthey
The Secretary
Queensland Law Reform Commission
PO Box 13312
George Street Post Shop
Brisbane QLD 4006

Via email to: lawreform.commission@justice.qld.gov.au

Dear Mrs Manthey,

Thank you for the opportunity to make a submission in response to the Queensland Law Reform Commission's *A legal framework for voluntary assisted dying Consultation Paper*.

The position of Public Advocate is established under the *Guardianship and Administration Act 2000* (Qld). Broadly speaking, the role of the Public Advocate is to promote and protect the rights and autonomy of Queensland adults with impaired decision-making capacity, and their participation in all aspects of community life. More specifically, the Public Advocate is to undertake systemic advocacy to:

- promote and protect the rights of adults with impaired decision-making capacity for a matter;
- promote the protection of them from neglect, exploitation or abuse;
- encourage the development of programs to help them reach the greatest practicable degree of autonomy;
- promote the provision of services and facilities for them; and
- monitor and review the delivery of services and facilities to them.[3]

In line with my role, this submission concentrates on the questions in the Consultation Paper that specifically affect people with impaired decision-making capacity.

Q-1 What principles should guide the Commission's approach to developing voluntary assisted dying legislation?

Q-2 Should the draft legislation include a statement of principles:

(a) that aids in the interpretation of the legislation?

(b) to which a person must have regard when exercising a power or performing a function under the legislation (as in Victoria and Western Australia)?

I support the Commission's use of guiding principles when developing draft voluntary assisted dying legislation and the inclusion of a statement of principles in the draft legislation to assist with the interpretation and application of the legislation.

[3] *Guardianship and Administration Act 2000* (Qld) s 209.

The Consultation Paper highlights that the *Human Rights Act 2019* (Qld) provides important guidance for the development of legislation and gives statutory expression to a number of fundamental personal rights.[4] I respectfully suggest that the *Guardianship and Administration Act* should also be used to guide the draft legislation. The 2019 amendments to the *Guardianship and Administration Act* come into force on 30 November 2020 and contain a set of General Principles that the community is encouraged to apply.

The General Principles in the *Guardianship and Administration Act* were revised to more closely align with the *Convention on the Rights of Persons with Disabilities*. They articulate the presumption of capacity and that people with impaired capacity have the same fundamental rights and freedoms as people without disability. These rights, along with those in the *Human Rights Act*, will need to be balanced with other rights and interests, as articulated in the Consultation Paper.[5]

The *Guardianship and Administration Act* also stipulates people's right to adequate and appropriate support for decision-making.[6] This applies to all types of decisions, and should also apply to those associated with voluntary assisted dying, where the person has sufficient capacity (with support) for that decision.

Q-6 Should the eligibility criteria for a person to access voluntary assisted dying expressly state that a person is not eligible only because they:

(a) have a disability; or

(b) are diagnosed with a mental illness?

People living with disability and/or mental illness should be afforded the same rights as other members of the community and not be discriminated against or denied access to any service or opportunity based on a diagnosis of disability or mental illness. Doing so would amount to discrimination based on an attribute under the *Anti-Discrimination Act 1991* and the right to recognition before the law without discrimination under s 15 of the *Human Rights Act*.[7]

I agree with the views of the Parliamentary Committee that recommended a person who is otherwise eligible to access the voluntary assisted dying scheme not be rendered ineligible only because the person has a mental health condition, provided the person has the requisite decision-making capacity.[8] I respectfully suggest that this also extends to people with disability, including intellectual and cognitive disability.

P-3 The draft legislation should provide that, for a person to be eligible for access to voluntary assisted dying, the person must have decision-making capacity in relation to voluntary assisted dying.

Q-12 Should 'decision-making capacity' be defined in the same terms as the definition of 'capacity' in the *Guardianship and Administration Act 2000* and the *Powers of Attorney Act 1998*, or in similar terms to the definitions of 'decision-making capacity' in the voluntary assisted dying legislation in Victoria and Western Australia? Why or why not?

Q-13 What should be the position if a person who has started the process of accessing voluntary assisted dying loses, or is at risk of losing, their decision-making capacity in relation to voluntary assisted dying before they complete the process?

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[4] Queensland Law Reform Commission, *A legal framework for voluntary assisted dying Consultation Paper*, WP No 79 (October 2020) 26.

[5] Ibid 27.

[6] *Guardianship and Administration Act 2000* (Qld) s 6.

[7] *Human Rights Act 2019* (Qld) s 15.

[8] Health, Communities, Disability Services and Domestic and Family Violence Prevention Committee, Parliament of Queensland, *Voluntary assisted dying* (Report No 34, March 2020) rec 10.

For example:

(a) Should a person who loses their decision-making capacity become ineligible to access voluntary assisted dying?

(b) Should there be any provisions to deal with the circumstance where a person is at risk of losing their decision-making capacity, other than allowing for a reduction of any waiting periods? If so, what should they be?

Note: see also [6.16] ff and Q-20 and Q-21 below as to waiting periods.

(c) Should a person be able, at the time of their first request, to give an advance directive as to specific circumstances in which their request should be acted on by a practitioner administering a voluntary assisted dying substance, despite the person having lost capacity in the meantime?

The first matter to be dealt with in responding to these questions is the definition of 'capacity' that should apply under any voluntary assisted dying legislation. It is suggested that 'capacity' in the draft legislation should be defined in the same terms as the definition in the *Guardianship and Administration Act*:[9]

> **capacity**, for a person for a matter, means the person is capable of—
>
> (a) understanding the nature and effect of decisions about the matter; and
>
> (b) freely and voluntarily making decisions about the matter; and
>
> (c) communicating the decisions in some way.

There are a number of reasons why this this definition should be used. Primarily, the definition of capacity in the *Guardianship and Administration Act* is recognised as established law in Queensland regarding the determination of people's capacity for personal matters, including consenting to, or refusing, medical treatment. However, there are other definitions of capacity for certain legal purposes that can create confusion. For example, the *Mental Health Act 2016,* establishes treatment criteria for the involuntary treatment of a person with mental illness, which include the capacity to consent to treatment. The Act contains a definition of capacity for this purpose that is similar to, but different from, that used under the *Guardianship and Administration Act.* There are also legal definitions of 'unsoundness of mind' and 'fitness for trial' under the *Mental Health Act,* that also touch on issues of capacity, relating to the prosecution of criminal charges, but again, apply different criteria.

Accordingly, while the definition of capacity for civil legal matters is well established, there remains a level of uncertainty and confusion in the Queensland community about its meaning and application, including among some legal practitioners.

Considering the seriousness of the decisions to be made by people seeking to access voluntary assisted dying, it is critical that the new legislation does not contribute to the confusion around the definitions of capacity for different purposes. The adoption of the definition of capacity in the *Guardianship and Administration Act* is supported for the draft legislation. Further, if the definition is consistent, reviews of decisions made to the Queensland Civil and Administrative Tribunal (discussed below) would be determined by members who are familiar with interpreting and applying this definition of capacity.

On the issue whether a person's capacity should be 'enduring' once they have started the process of accessing voluntary assisted dying, a proposal to permit people to give an advance health directive providing specific direction in relation to voluntary assisted dying after the person has lost capacity, is not supported. Nor are any provisions that would provide for a person to access voluntary assisted dying after they have lost capacity for that decision, even when they may have commenced the process to access voluntary assisted dying.

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[9] See *Guardianship and Administration Act,* Sch 4, Dictionary.

Any future voluntary assisted dying legislation should not permit people to consent to, or actively seek, voluntary assisted dying in any advanced care planning documents, such as Enduring Powers of Attorney or Advance Health Directives, or in any other health planning documents (such as Statement of Choices, Advance Health Directive for Mental Health etc.). There should be no possibility that a person can make a decision to voluntarily end their life, or have others end their lives, after they have lost capacity for decision-making about the issue.

The power to make such a decision should never be conferred on a substitute decision-maker such as an enduring attorney, guardian or statutory health attorney. Queensland's guardianship and power of attorney legislation does not permit certain decisions to be made by substitute decision-makers, including, for example, consent to marriage, the making or revoking of a will, voting, the termination of a pregnancy, sterilisation or organ donation.[10] Decisions relating to voluntary assisted dying should be regarded as a similar decision.

Most international laws, and the voluntary assisted dying legislation recently passed in Victoria, require that a person must have the decision-making capacity to request to die voluntarily. In Victoria, two separate tests of decision-making capacity are required to be conducted by two different health professionals, prior to any request being considered.[11] However, it is acknowledged that two countries in Europe (the Netherlands and Belgium) are now beginning to grant access to voluntary assisted dying for people suffering from dementia or psychiatric illnesses.[12]

I am aware that many submissions were made to the Parliamentary Committee that recounted people's experiences and distress about a family member or friend who lost decision-making capacity (from dementia or Alzheimer's or another progressive, aged-related illness) before death and advocated for voluntary assisted dying to be accessible by people who have lost decision-making capacity. While acknowledging the extreme distress that the deterioration in a loved one's capacity can cause, any law that would permit a person to access voluntary assisted dying after losing decision-making capacity is not supported.

This is not to say that people who may be experiencing some deterioration in their decision-making capacity should be automatically excluded from accessing voluntary assisted dying. Rather, their capacity to make this decision up to the time of their death would need to be carefully assessed, and their right to have support to make that decision, also recognised and facilitated. To that end, the suggestion to reduce waiting periods for people experiencing progressive conditions is supported in principle.

In summary, any future voluntary assisted dying legislation should include the necessary safeguards to ensure that only people with decision-making capacity can access voluntary assisted dying. Once a person loses decision-making capacity for this decision they should be ineligible to access voluntary assisted dying.

Q-25 Should the draft legislation provide for an eligible applicant to apply to the Queensland Civil and Administrative Tribunal for review of a decision of a coordinating practitioner or a consulting practitioner that the person who is the subject of the decision:

(a) is or is not ordinarily resident in the State (as in Victoria);

(b) at the time of making the first request, was or was not ordinarily resident in the State for a specified minimum period (as in Victoria and Western Australia);

(c) has or does not have decision-making capacity in relation to voluntary assisted dying (as in Victoria and Western Australia);

(d) is or is not acting voluntarily and without coercion (as in Western Australia)?

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[10] *Guardianship and Administration Act* 2000 (Qld).
[11] *Voluntary Assisted Dying Act 2017 (*Vic).
[12] Emanuel EJ, Onwuteaka-Philipsen BD, Urwin JW, Cohen J.Attitudes and practices of euthanasia and physician-assisted suicide in the United States, Canada and Europe. JAMA. 2016; 316(1):79-90.

Q-26 If yes to Q-25, should an application for review be able to be made by:
(a) the person who is the subject of the decision;
(b) an agent of the person who is the subject of the decision; or
(c) another person who the tribunal is satisfied has a special interest in the medical care and treatment of the person?

The ability to seek a review of a finding by a medical practitioner regard a person's capacity before the Queensland Civil and Administrative Tribunal (QCAT) is supported. This will provide an additional safeguard when determining the critical question of capacity in this process. QCAT already has the jurisdiction to determine decision-making capacity,[13] and such reviews could conceivably be undertaken using that provision without requiring further amendments to the *Guardianship and Administration Act*. This is especially so if the definition of capacity adopted for voluntary assisted dying is the same as that under the *Guardianship and Administration Act*.

It is important to make the point here, that the draft legislation should not assume, or be drafted in a way that suggest,s that a finding by a medical practitioner regarding a person's decision-making capacity, amounts to a legal determination of capacity. There is already a level of confusion in the community about the status of a medical assessment of capacity, versus a determination by QCAT.

Regarding who should be eligible to make such applications, the relevant provision in the *Guardianship and Administration Act* could be of assistance. The suggestion that the categories of interested parties include both the individual themselves or another person who QCAT determines is an 'interested person' is supported in principle. However, consideration should be given to adopting the definition of 'interested person' in the *Guardianship and Administration Act,* which is defined as a person who has a 'sufficient and continuing interest in the other person' the subject of the application.[14] This definition would provide flexibility for QCAT to determine the suitability of other people making the application, while also having precedents to guide these determinations.

Thank you for the opportunity to make a submission on the very important considerations and issues associated with drafting voluntary assisted dying legislation for Queensland. Should the opportunity arise, I would be pleased to be part of further discussions in relation to the development of the legislation or any issues raised in my submission.

Yours sincerely,

Mary Burgess
Public Advocate

[13] *Guardianship and Administration Act 2000* (Qld) s 146.
[14] Ibid sch 4.