

27 November 2020

The Secretary
Queensland Law Reform Commission
PO Box 13312 George Street Post Shop
Queensland 4003

Email: lawreform.commission@justice.qld.gov.au

Dear Queensland Law Reform Commission Secretariat,

Re: Law Reform Commission's Consultation Paper: A legal framework for voluntary assisted dying

Thank you for the opportunity to respond to the Law Reform Commission's 'Consultation Paper: A legal framework for voluntary assisted dying'¹ which arose from the Inquiry into Aged Care, End-of-Life, Palliative Care, and Voluntary Assisted Dying conducted by the Health, Communities, Disability Services and Domestic and Family Violence Prevention Committee.²

Palliative Care Queensland (PCQ) is the peak body for palliative care in Queensland. Our priorities are that all Queenslanders are able to live every day until their last, are able to have a dignified death, regardless of their illness, age, culture or location, have access to a supportive social network at the end phase of life, and have the choice of quality palliative care.

We appreciated the Inquiry's acknowledgement of the work and contribution of our organisation in Queensland and are pleased that the importance of palliative care for our health care system, communities and individuals was highlighted throughout Report No. 33.³

Regarding Voluntary Assisted Dying (VAD), PCQ remains neutral in that we do not advocate for, nor argue against the introduction of VAD, having amongst our membership people who strongly support and just as strongly oppose VAD. Though VAD is not a component of palliative care practice, we wish to reply to the Law Reform Commission's Consultation Paper on VAD, given VAD's implications and potential impact on palliative care provision in Queensland. We put forward three main points for consideration.

1 Queensland Law Reform Commission (2020) A legal framework for voluntary assisted dying: Consultation Paper. Accessed online: [https://www.qlrc.qld.gov.au/_data/assets/pdf_file/0003/658506/qlrc-wp-79-2020.pdf](https://www qlrc.qld.gov.au/_data/assets/pdf_file/0003/658506/qlrc-wp-79-2020.pdf)

2 Health, Communities, Disability Services and Domestic and Family Violence Prevention Committee (2020) Voluntary assisted dying. Report No. 34, 56th Parliament. Accessed online: <https://www.parliament.qld.gov.au/Documents/TableOffice/TabledPapers/2020/5620T490.pdf>

3 Health, Communities, Disability Services and Domestic and Family Violence Prevention Committee (2020). Aged care, end-of-life and palliative care: Report No. 33, 56th Parliament. Accessed online: <https://www.parliament.qld.gov.au/Documents/TableOffice/TabledPapers/2020/5620T466.pdf>

First, PCQ requests that legislation supporting and enshrining palliative care should be considered at the same time as VAD legislation. We argue that lack of access to high quality palliative care should never be the reason to consider VAD in Queensland in order to end 'intolerable suffering'. Queensland's palliative care system is grossly underfunded and this lack of access to palliative care services could mean that some Queenslanders choose VAD out of fear that they will not be adequately cared for as they die.

Interstate and overseas experience suggests that less than 1% of people with a terminal illness are likely to access VAD, and based on PCQ's previous work, we argue that access to high quality palliative care and end-of-life services could improve the lives and the deaths of 100% of Queenslanders. Governments must increase palliative care funding before the legalisation of VAD, and it must be stipulated that any funds that are directed towards VAD are not removed from palliative care budgets. For an overview of requirements to transform palliative care systems for Queenslanders, please refer to Key Document 4 'Palliative Care in Queensland: Requirements for New Investment to Transform Care' (on page 14 of the attachment).

Second, we request that a number of principles be considered in the further development of VAD legislation, including the continued separation of VAD from palliative care frameworks, since euthanasia and physician-assisted suicide are not part of palliative care practice.

Key guiding principles are listed in three Key Documents attached to this letter:

1. A PCQ Position Statement on VAD (including considerations for end of life and voluntary assisted dying legislation),
2. PCQ's Guiding principles for those providing care to people living with a life-limiting illness, and
3. PCQ's Interim response to the Queensland Parliament Report No. 34: Voluntary assisted dying *This details PCQ's recommendations for legislative consideration alongside the Inquiry Recommendations.*

Finally, as the next stage of VAD legislative review commences, we request that the Queensland Law Reform Commission undertake further robust and transparent deliberations with the palliative care community and other relevant stakeholders prior to the confirmation of legislation. As discussions about VAD legislation continue, conversations are needed regarding the context of palliative care, how to improve access to palliative care services, how to support those patients who are considering VAD, and how to support, respect and protect the health professionals and entities which care for people with life-limiting illness.

PCQ would welcome the opportunity to be involved in consultation groups that further examine issues related to VAD. PCQ is ideally positioned to engage and develop partnerships and lead initiatives through established positive relationships with consumers, community members, community groups, Local Government Authorities and the health, aged care and social care sectors.



Furthermore, our network of palliative care specialist teams can help map the palliative patient journey and the changing needs of the dying person and their loved ones at each stage, which is particularly important to consider as the parameters of VAD legislation are determined. These are the professionals who can discuss ceilings of care, and to give a realistic understanding of the palliative supports they can provide to patients, which would allow patients to make more informed choices about their future. They can also speak to the system infrastructure that needs to be scaled up regarding both specialist and generalist palliative care services and supports, should VAD legislation be enacted.

Thank you for this opportunity to put forward our concerns and recommendations. We appreciate the tremendous task before you, and look forward to further conversations with you as the deliberations continue.

Sincerely yours,

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Attached: Palliative Care Queensland's key documents in relation to Voluntary Assisted Dying



Palliative Care Queensland's key documents in relation to Voluntary Assisted Dying

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Key Document 1: Palliative Care Queensland Position Statement on Voluntary Assisted Dying

Preamble: The majority of the following text comes from Palliative Care Australia's 'Position Statement on Voluntary Assisted Dying'¹ with some content added by Palliative Care Queensland.

Additional content has not been reviewed by Palliative Care Australia and therefore should not be taken as an endorsement of Palliative Care Australia's policies.

As a member organisation of Palliative Care Australia, Palliative Care Queensland strongly affirms the following guidelines and principles, adapts them to the Queensland context, and submits them to the Queensland Law Reform Commission for further consideration in response to Question 50, which asks:

What key issues or considerations should be taken into account in the implementation of voluntary assisted dying legislation in Queensland?²

Palliative Care Queensland (PCQ) recognises that the topic of voluntary assisted dying raises difficult and complex ethical issues, and that there is a broad spectrum of opinion and a level of support for reform within the Queensland community which reflects diverse cultures, belief systems and populations. PCQ recognises that this diversity of opinion is also reflected within the palliative care community.

A decision about whether or not to legalise voluntary assisted dying is one for governments. PCQ neither advocates for, nor argues against the legalisation of voluntary assisted dying.

Voluntary assisted dying is not part of palliative care practice

It is important to recognise the difference between palliative care and voluntary assisted dying. We promote the following distinctions between the two:

» Palliative care³ affirms life, and regards dying as a normal process that intends neither to hasten nor postpone death. It 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.

» Voluntary assisted dying⁴ is where medical practitioners may prescribe and potentially directly administer an approved substance for the purpose of causing death where the person meets the eligibility criteria outlined in the relevant legislation and has sought this outcome voluntarily.

1 Palliative Care Australia (2019) Position Statement on Voluntary Assisted Dying. Accessed online: https://palliativecare.org.au/wp-content/uploads/dlm_uploads/2019/09/2019-VAD-position-statement-Final.pdf

2 Queensland Law Reform Commission (2020) A legal framework for voluntary assisted dying: Consultation Paper. Accessed online: https://www.qirc.qld.gov.au/_data/assets/pdf_file/0003/658506/qirc-wp-79-2020.pdf

3 World Health Organisation and Worldwide Palliative Care Alliance (2014) Global Atlas of Palliative Care at the End of Life [accessed online]

4 Per the Voluntary Assisted Dying Act 2017 (Victoria) which defines voluntary assisted dying as the administration of a voluntary assisted dying substance (a poison or controlled substance or a drug of dependence for the purpose of causing death) and includes steps reasonably related to such administration. It is intended to incorporate other descriptions including medical assistance in dying, physician assisted suicide, and voluntary euthanasia.

Palliative Care Queensland's key documents in relation to Voluntary Assisted Dying

With regard to palliative care and voluntary assisted dying, Palliative Care Queensland believes that:

- » If palliative care health professionals or organisations choose to offer and provide voluntary assisted dying for their patients with life-limiting illness, this is a practice separate from palliative care.
- » In Queensland, an individual's choice to explore voluntary assisted dying should never be a choice based on a lack of access to palliative care.
- » Palliative care is explicitly recognised under the human right to health.⁵ Every Queenslanders living with a life-limiting illness should always have equitable access to quality needs-based palliative care at any point in their illness journey, with timely referral to specialist palliative care⁶ if required.
- » Palliative care is person and family-centred care with the primary goal to ensure patient safety and to optimise the quality of life, as palliative care helps people live their life as fully and as comfortably as possible when living with a life-limiting illness.⁷
- » When aligned with a person's preferences, withdrawing or refusing life sustaining treatment (including withholding artificial hydration) or providing strong medication(s) to relieve suffering, do not constitute voluntary assisted dying.

Respecting the workforce which cares for people with life-limiting illness

PCQ recognises that health professionals providing palliative care may be asked for information about voluntary assisted dying or receive direct requests from people with life-limiting illness to access voluntary assisted dying.

- » All people providing palliative care should be supported to ensure people with life-limiting illness in their care receive safe, compassionate, competent care regardless of whether they seek information about, or referral to, services that may provide voluntary assisted dying.
- » It is the right of health professionals providing palliative care to make appropriate judgements about whether they will be involved in voluntary assisted dying based on their personal ethics and beliefs and those of the organisation/s by which they are employed. Voluntary assisted dying should not be considered part of palliative care service delivery. Healthcare organisation/s should also be legally protected with the right to conscientiously object to the provision of voluntary assisted dying within their facilities.
- » All people working in palliative care should be treated respectfully and demonstrate professional behaviour towards colleagues and co-workers regardless of their views on voluntary assisted dying and the decision to exercise their right to conscientiously object or conscientiously participate in any aspect of voluntary assisted dying.

As indicated in Key Document 2, Palliative Care Australia has developed 'Voluntary Assisted Dying in Australia: Guiding principles for those providing care to people living with a life-limiting illness' to assist health professionals, care workers and volunteers who are providing care to people living with

⁵ WHA, Resolution WHA67.19, Strengthening of palliative care as a component of comprehensive care throughout the life course, May 24, 2014.

⁶ Specialist palliative care comprises of multidisciplinary teams with specialised skills, competencies, experience and training in palliative care, and is one component of broader palliative care service delivery. Source: World Health Organisation (2018) Fact sheet: Palliative Care [accessed online], Palliative Care Australia 2018 Palliative Care Service Development Guidelines.

⁷ Palliative Care Australia (2018) Palliative Care 2030 – working towards the future of quality palliative care for all, PCA, Canberra.

Palliative Care Queensland's key documents in relation to Voluntary Assisted Dying

a life-limiting illness, or working in or engaging with organisations providing any level of palliative care. It is recommended that the Guiding Principles be used alongside relevant legislation, organisational ethical frameworks and codes of conduct.

Considerations for end of life and voluntary assisted dying legislation

As the Queensland Government contemplates reform of the law to permit voluntary assisted dying in limited circumstances, the Queensland Government should consider the following:

- » People with a life-limiting illness should be able to make informed and autonomous decisions about their care, and be provided with the opportunity to discuss needs, hopes and care preferences consistent with their personal values, culture, beliefs and goals. Legislation should ensure patients are advised of the palliative care options available to them.
- » Discussions regarding voluntary assisted dying for a person with a life-limiting illness must only be initiated by the patient (and not by their family or health professionals).
- » Health professionals and health service entities should be provided with legislative protection to ensure they are not required to undertake any acts which conflict with their personal or professional values.
- » Any legislation should promote high-quality care and ensure patient safety. This includes ensuring patients will receive ongoing and safe continuity of care across settings and throughout the course of a person's illness.
- » The cost of developing and implementing voluntary assisted dying in Queensland must come from new funds – the funds should not be divested from palliative care funding.
- » Governments should invest in research including data collection related to voluntary assisted dying to enable review of any scheme, the monitoring of safe practice and assess the impacts of voluntary assisted dying including the impact on patients, their families, their carers and personal supporters. In addition, investment will also be necessary to research the impact (including the cultural impact) that the introduction of voluntary assisted dying has on the health workforce. As above, the funds for this research should not be diverted from palliative care, but must instead be funded in addition to any palliative care funding or research.
- » The next stage of voluntary assisted dying development of laws, regulations and guidelines must be undertaken in consultation with medical and health experts. Development of the Victorian VAD legislation was guided by ethicists, lawyers, palliative care health professionals and others, and Queensland should have a similar format.
- This must include extensive consultation with palliative care and other health professionals on the White and Willmott Bill.
- » The risk due to the absence of uniform legislation across Australia and the risk of eroding safeguards, including 'VAD tourism', consumer confusion and health professional uncertainty.

For an elaboration on selected points above, please see Key Document 3 entitled 'Palliative Care Queensland - Interim response to the Queensland Parliament Report No. 34: Voluntary assisted dying' which connects selected considerations to the recommendations made in the Inquiry Report.

Palliative Care Queensland's key documents in relation to Voluntary Assisted Dying

Further investment is required to meet Queensland's palliative care needs

Investment at national, state and territory levels will be required to ensure that the systems and people are available to provide quality palliative care where and when it is needed.⁸

There is significant unmet need for high quality palliative care in Queensland and forecasts indicate significant increases in need in the years ahead.⁹

PCQ calls for:

- » Substantial coordinated investment by all jurisdictions to plan and prepare for the future where Queenslanders will live longer, demand an improved quality of life, and access to high quality palliative care when living with a life-limiting illness.
- » An investment in growing the specialist palliative care workforce, and increased support for the acute, primary care, aged care sectors and public health palliative care to provide quality palliative care as part of their core business.
- » Further investment to ensure an adequately resourced and appropriately trained health workforce who are familiar with the broader aspects of palliative care provision, including clinical, legal, and ethical aspects. Particularly important is developing advanced communication skills to actively listen and engage in respectful dialogue with people about their end of life preferences. The palliative care workforce supports people with life-limiting illness by enabling exploration of the complex social, spiritual, cultural, psychological, emotional and physical aspects of their care preferences.
- » Compulsory palliative care education for all medical, nursing, allied health and pharmacy students as part of undergraduate curriculum to ensure a consistent baseline competency in palliative care pain and symptom management, together with the communication skills required for caring for people with life-limiting illness, their families and carers.
- » Palliative care to be included as a component of all health and aged care quality standards.
- » The difference between palliative care and voluntary assisted dying to be made clear at all times, supported by a fully resourced and sustained state public awareness campaign about palliative care, what it offers and how and when it can be accessed.

For information on the nature of the investment required, please refer to Key Document 4 entitled 'Palliative Care in Queensland: Requirements for New Investment to Transform Care', which can be downloaded from our website: www.palliativecareqld.org.au/publications-resources.

⁸ Australian Government, National Palliative Care Strategy 2018, page 20.

⁹ Australian Government Productivity Commission, Introducing Competition and informed User Choice into Human Services: Reforms to Human Services, No.85, 27 October 2017. [accessed online]

Key Document 2: Guiding principles for those providing care to people living with a life-limiting illness

Preamble: The majority of the following text comes from Palliative Care Australia's document entitled 'Guiding principles for those providing care to people living with a life-limiting illness'¹⁰ with some content added by Palliative Care Queensland.

Additional content has not been reviewed by Palliative Care Australia and therefore should not be taken as an endorsement of Palliative Care Australia's policies.

As a member organisation of Palliative Care Australia, Palliative Care Queensland strongly affirms the following guidelines and principles, adapts them to the Queensland context, and submits them to the Queensland Law Reform Commission for further consideration in response to Question 50, which asks:

What key issues or considerations should be taken into account in the implementation of voluntary assisted dying legislation in Queensland?¹¹

Why are these guiding principles necessary?

Palliative Care Queensland (PCQ) acknowledges that where introduced or being considered, legislation within Australian jurisdictions that legalises voluntary assisted dying¹² will pose many ethical, personal and professional issues for health professionals, care workers and volunteers who are providing care to people living with a life-limiting illness, or working in or engaging with organisations providing any level of palliative care.

The purpose of these guiding principles is two-fold:

1. To ensure appropriate care is provided to a person living with a life-limiting illness at all times; and
2. To maintain appropriate, respectful and cooperative relationships between health and care professionals.

There are seven guiding principles of equal importance that are designed to sit alongside legislation (if applicable), organisational ethical frameworks or professional codes of conduct. Underpinning these principles are the following fundamental elements of palliative care:

- A person and family-centred approach to care accepts that an illness has an impact on both the individual and their family¹³ and carers.

10 Palliative Care Australia (2019). Voluntary Assisted Dying in Australia: Guiding principles for those providing care to people living with a life-limiting illness. Accessed online: https://palliativecare.org.au/wp-content/uploads/dlm_uploads/2019/06/PCA-Guiding-Principles-Voluntary-Assisted-Dying.pdf

11 Queensland Law Reform Commission (2020) A legal framework for voluntary assisted dying: Consultation Paper. Accessed online: https://www.qirc.qld.gov.au/__data/assets/pdf_file/0003/658506/qirc-wp-79-2020.pdf

12 In this document the term voluntary assisted dying is used to be consistent with the Voluntary Assisted Dying Act 2017 (Victoria) which defines voluntary assisted dying as the administration of a voluntary assisted dying substance (a poison or controlled substance or a drug of dependence for the purpose of causing death) and includes steps reasonably related to such administration. It is intended to incorporate other descriptions including medical assistance in dying, physician assisted suicide, and voluntary euthanasia.

13 Family includes self-designated family.

Palliative Care Queensland's key documents in relation to Voluntary Assisted Dying

- Dying is a normal part of life and is a human experience not just a biological or medical event.
- All care is based on patient safety, current and comprehensive clinical assessment, delivered in accordance with the person's expressed values, goals of care and preferences, and informed by the best available evidence.
- Distress caused by symptoms (physical, psychosocial or spiritual) is actively pre-empted, and when it occurs, the response is timely and effective with the dignity of the person prioritised at all times.
- Suffering is a multidimensional experience not confined to physical symptoms, which is subjective and unique to an individual, often involving psychological distress and existential concerns that must be explored appropriately.

Who do these principles apply to?

The coordination of care for people living with a life-limiting illness may be undertaken by a wide range of professionals across many organisations and settings. People will have different levels of need for palliative care, which may vary over time, increasing or decreasing in complexity.

This includes:

- People who provide palliative care as part of a broader scope of practice such as general practitioners, nurses, pharmacists, allied health professionals and aged care workers.
- Specialist palliative care¹⁴ team members including palliative care physicians, nurse practitioners, palliative care nurses, specialist allied health, grief and bereavement counsellors, and spiritual care and pastoral care workers
- Care and support workers and volunteers in organisations or settings where they may interact with people who are living with a life-limiting illness or people nearing the end of their life.

The guiding principles

Principle 1: People living with a life-limiting illness are supported and respected whether or not they choose to explore or access voluntary assisted dying

People living with a life-limiting illness, their families and carers must be treated with dignity and respect, and supported to explore suffering and options available, which may include voluntary assisted dying where this is legally¹⁵ available. Individuals, their families and carers should also be supported to identify and maintain caring networks, including after death.

Health professionals, care workers and volunteers should:

¹⁴ Specialist palliative care comprises of multidisciplinary teams including medical practitioners, nurse practitioners, nurses and allied health and other professionals, most of whom will have specialist qualifications, extensive experience and skills in palliative care (and for whom this is their substantive role and area of practice) to support people with more complex and persistent needs. Source: Palliative Care Australia (2018) Palliative Care Service Development Guidelines [online].

¹⁵ Within the parameters of respective legislative requirements related to initiating discussions and providing information.

Palliative Care Queensland's key documents in relation to Voluntary Assisted Dying

- Support people living with a life-limiting illness to make informed and autonomous decisions about their care.
- Prioritise the opportunity to discuss needs, hopes and preferences with individuals that are consistent with personal values, experiences, culture, beliefs and goals of the person with a life-limiting illness.
- Be familiar with the broader aspects of palliative care provision, including physical, emotional, spiritual and social care that may support a person exploring voluntary assisted dying.
- Recognise that a person living with a life-limiting illness may have specific family members or friends they want to be involved in and informed about their end of life decisions.

Principle 2: People exploring voluntary assisted dying will not be abandoned

At all times care must be taken to ensure an individual can receive safe, compassionate, competent care regardless of whether they seek information about, or referral to, services that may provide voluntary assisted dying. A person living with a life-limiting illness, their family and carers should not feel abandoned, or fear that care will be adversely affected if they want to explore voluntary assisted dying.

Health professionals, care workers and volunteers should:

- Be advocates for palliative care, and if required clarify that palliative care and voluntary assisted dying are different, where palliative care “is an approach that intends neither to hasten nor postpone death”.¹⁶
- Advise a person with a life-limiting illness that palliative care is always available even if they are considering voluntary assisted dying.
- Be supported to explain when it may not be possible to provide care that matches an individual's preferences and provide the opportunity to discuss alternative available options.
- Commit to ensuring there is adequate communication, which may involve multiple teams or multiple health or aged care organisations and locations.
- Ensure people living with a life-limiting illness do not have undue delays to access voluntary assisted dying, when health professionals, organisations or services exercise the right to conscientious objection.
- Consider when referral to specialist palliative care would assist when there are more complex and persistent needs.

¹⁶ Palliative care is an approach that intends neither to hasten nor postpone death. It 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. Source: World Health Organization www.who.int/cancer/palliative/definition/en

Palliative Care Queensland's key documents in relation to Voluntary Assisted Dying

Principle 3: Respectful and professional behaviour towards colleagues and co-workers regardless of their views on voluntary assisted dying

In any setting where care is provided to people living with a life-limiting illness, there may be different views between health and care professionals about voluntary assisted dying and what options should or can be offered and accessed. There will also be decisions at the organisational level that will determine the extent of involvement in voluntary assisted dying within a specific setting.

Health professionals, care workers and volunteers should:

- Be supported to work within their own professional or personal ethical values, whilst continuing to provide safe, quality, compassionate care to people living with a life-limiting illness.
- Be treated with mutual understanding and respect, facilitated by open and transparent communication.
- Be able to exercise their right to conscientiously object or conscientiously participate in any aspect of voluntary assisted dying.
- Have their privacy and confidentiality maintained.

Principle 4: Effective communication is an important part of quality care

Communication with a person living with life-limiting illness, their family and carers regarding their end of life and care options, including when voluntary assisted dying is raised, involves both giving and receiving information at a time where emotions and stress can affect everyone involved in the conversation. Spending time to listen and talk is essential to explore a person's beliefs, values, concerns, understanding of, and preferences for care.

Health professionals and care workers should:

- Be provided with opportunities to build on their communication skills, including those related to cultural appropriateness, exploring suffering and recognising the impact of a discussion on all participants.
- Be given the time to prepare for and have respectful and compassionate discussions over time.
- Ensure any individual requesting information on, or access to, voluntary assisted dying feels supported during all conversations.

Principle 5: Ongoing development of knowledge, skill and confidence is required to provide competent and safe care to people living with a life-limiting illness

Access to information, coupled with inter-professional learning and specific learning opportunities based on profession and scope of practice, are essential for those working or engaging within any setting providing care to people living with a life-limiting illness.

Health professionals, care workers and volunteers should:

- Be aware of their own training and education needs, particularly in relation to having conversations about end-of-life, pain and other symptom management, recognising deterioration, grief and bereavement and self-care.

Palliative Care Queensland's key documents in relation to Voluntary Assisted Dying

- Be supported to prioritise self-awareness and self-care strategies that include both physical and emotional health, and actively manage distress.
- Be aware of ethical, policy and research developments that may impact on their provision of care.
- Be provided with easy access to appropriate opportunities to maintain and improve their knowledge, confidence and skills specific to roles and scopes of practice, where cultural awareness and culturally safe practice is a vital part of learning at all levels.
- Have a clear understanding of legal frameworks, processes and referral pathways if a person living with a life-limiting illness chooses to explore voluntary assisted dying.

Principle 6: Self-care practice is a shared responsibility between individuals, colleagues and organisations

Providing person and family-centred care at the end of an individual's life is rewarding and satisfying much of the time, however it can also be overwhelming and difficult. Developing skills to deal with complicated or emotionally challenging situations, as individuals and within teams, must be supported by a systematic approach to identifying warning signs of stress and burnout.

Health professionals, care workers and volunteers should:

- Be encouraged to participate in opportunities that build resilience and facilitate effective communication within teams, including reflection, debriefing, professional supervision and mentoring.
- Be supported when involvement with any aspect of voluntary assisted dying causes emotional or professional distress.
- Have access to prompt confidential supportive services, relevant to individual need, role and scope of practice, regardless of choosing to conscientiously object or conscientiously participate in any aspect of voluntary assisted dying, or working within an organisation that does or does not facilitate access to voluntary assisted dying.

Principle 7: Continue to learn from evidence and evolving practice to drive quality improvement in voluntary assisted dying

The evidence base, legal requirements and policy developments related to voluntary assisted dying are evolving rapidly in Australia and internationally.

Health professionals, care workers and volunteers should:

- Be encouraged to participate and collaborate in research and data collection related to voluntary assisted dying to enable review of any scheme, and the monitoring of safe practice and the impacts of introduction in Australia.
- Be supported to learn from best practice in the Australian and international context to be able to implement quality improvements in voluntary assisted dying.
- Advocate for transparent public reporting on voluntary assisted dying as a mechanism to improve patient safety.

Key Document 3: Palliative Care Queensland - Interim response to the Queensland Parliament Report No. 34: *Voluntary assisted dying*

Introduction

Palliative Care Queensland (PCQ) is the peak body for palliative care in Queensland. Our priorities are that all Queenslanders are able to live every day until their last, are able to have a dignified death, regardless of their illness, age, culture or location, have access to a supportive social network at the end phase of life, and have the choice of quality palliative care.

PCQ provides this interim response to the Queensland Parliament Inquiry into aged care, end-of-life and palliative care and voluntary assisted dying Report No. 34 Voluntary assisted dying (Report No. 34) released on 31 March 2020. This follows the submission by PCQ to the Inquiry in April 2019¹⁷. We have provided a separate interim response to the Inquiry Report No. 33 Aged care, end-of-life and palliative care, and are preparing a detailed response to both Inquiry Reports. This will be developed in consultation with our broad membership of health professionals across all sectors of health, specialist and generalist palliative care services, aged care, disability care, peak bodies, consumers and interested members of the Queensland community.

PCQ remains neutral regarding Voluntary Assisted Dying (VAD) in that we do not advocate for, nor argue against the introduction of VAD, having amongst our membership people who strongly support and just as strongly oppose VAD. PCQ does however argue that lack of access to high quality palliative care should never be the reason to consider VAD in Queensland to end 'intolerable suffering'.

Interstate and overseas experience suggests that less than 1% of people with a terminal illness are likely to access VAD, and based on PCQ's previous work, we argue that access to high quality palliative care and end-of-life services could improve the lives and the deaths of 100% of Queenslanders. In reading this document, PCQ highlights Palliative Care Australia's Voluntary Assisted Dying in Australia: Guiding principles for those providing care to people living with a life-limiting illness¹⁸:

- People living with a life-limiting illness are supported and respected whether or not they choose to explore or access voluntary assisted dying
- People exploring voluntary assisted dying will not be abandoned
- Respectful and professional behaviour towards colleagues and co-workers regardless of their views on voluntary assisted dying
- Effective communication is an important part of quality care
- Ongoing development of knowledge, skill and confidence is required to provide competent and safe care to people living with a life-limiting illness

¹⁷ PCQ 'Palliative Care Queensland submission to the 2019 Queensland Parliament Inquiry into aged care, end-of-life and palliative care and voluntary assisted dying' 2019 [Online].

¹⁸ Palliative Care Australia. 'Voluntary Assisted Dying: Guiding principles for those providing care to people living with a life-limiting illness' 2019 [Online].

Palliative Care Queensland's key documents in relation to Voluntary Assisted Dying

- Self-care practice is a shared responsibility between individuals, colleagues and organisations
- Continue to learn from evidence and evolving practice to drive quality improvement in voluntary assisted dying.

Response to Inquiry Report No. 34

PCQ provides the following comments in this interim period to assist the Queensland Government in their response, and any additional deliberations by the Inquiry Committee whilst we prepare our submission. Most notably, we exercise caution in uncritically adopting the proposed VAD legislation (the White and Willmott Bill) as outlined in Inquiry Report No. 34. without robust and transparent consultation.

- Euthanasia and physician-assisted suicide are not part of palliative care practice. As discussions about VAD legislation are advanced, the context of palliative care and how to improve access to palliative care services is required.
 - The Committee do not make a recommendation with regards to access to palliative care¹⁹ or on the relationship and linkages that should exist between palliative care and VAD.
 - Legislation supporting and enshrining palliative care should be considered at the same time as VAD legislation.
- If the Queensland Parliament decides that VAD legislation should be introduced, the development of laws, regulations and guidelines must be undertaken in consultation with medical and health experts.
 - The Committee recommends the Queensland Government use the draft legislation put forward by academic lawyers of the Australian Centre for Health Law Research as the basis for legislation (Recommendation 1) - the White and Willmott Bill
 - Development of the Victorian VAD legislation was guided by ethicists, lawyers, palliative care health professionals and others – Queensland should have a similar format.
 - There needs to be extensive consultation with palliative care and other health professionals on the White and Willmott Bill, which has not been available for comment previously.
- Implementation of any VAD scheme needs to consider the existing and future capacity of an appropriately skilled workforce, and ensure its availability to meet the needs of people approaching the end of their life, in particular, workforce that sits outside of specialist palliative care.
 - The Committee do not make a recommendation related to ensuring resources for self-care and support for health professionals and organisations who choose to participate in or conscientiously object to VAD
- Processes to assist patients and families with impending death and a decision to choose VAD should be a core consideration, including bereavement support following VAD.

¹⁹ The Committee do make a comment on access to palliative care – “The committee recognises that palliative care needs to be adequately resourced and supported irrespective of whether voluntary assisted dying legislation is introduced or not and, if it is introduced, it is imperative that people have the full range of options available to them so that they can make an informed choice. Recommendations on palliative and end-of-life care are discussed in the committee’s report for this inquiry, Report No 33.” (7. Palliative care and voluntary assisted dying)

Palliative Care Queensland's key documents in relation to Voluntary Assisted Dying

- The Committee notes the importance of bereavement counselling but do not make a recommendation ensuring appropriate grief and bereavement services are available to families and communities
- The absence of uniform legislation across Australia and the risk of eroding safeguards, including 'VAD tourism', consumer confusion and health professional uncertainty.
 - The Committee comments (no recommendation) that if VAD is legislated in Queensland the implementation of the Victorian and Western Australian VAD schemes will provide a basis for the extent and types of material needed to guide both community members and medical practitioners for the Queensland VAD scheme.
 - This should include consideration of draft schemes in other jurisdictions such as Tasmania.
- If VAD legislation is introduced in Queensland, a minimum two-year period before it becomes active to provide time for the Queensland Government to ensure all necessary systems are in place and that there is an opportunity to learn from the Victorian implementation.
 - The Committee notes the White and Willmott Bill recommends a period of 18 months.
- Request that PCQ is involved in the following processes due to the implications and potential impact on palliative care provision in Queensland
 - Recommendation 7: The committee recommends that any voluntary assisted dying scheme in Queensland requires further research, consultation and examination to be undertaken with respect to improving end of life options for people who do not have decision-making capacity, particularly in relation to ensuring Advance Health Directives are fit for purpose and effective.
 - Recommendation 9: The committee recommends that any voluntary assisted dying scheme in Queensland includes comprehensive education campaigns to inform health practitioners and the general public about the scheme, its eligibility requirements and the rights and responsibilities of health practitioners.
 - Recommendation 19: The committee recommends that any voluntary assisted dying scheme in Queensland provides for the establishment of a review body similar to the Victorian Voluntary Assisted Dying Review Board to provide oversight of the scheme.
 - Recommendation 20: The committee recommends that any voluntary assisted dying scheme in Queensland requires that health practitioners involved in administering or conducting assessments for voluntary assisted dying complete mandatory training developed by the Department of Health in conjunction with peak health professional bodies.

**Key Document 4: Palliative Care in Queensland: Requirements for
New Investment to Transform Care'**

Please note: The document on the following pages is available to download from the Palliative Care Queensland website:

<https://palliativecareqld.org.au/publications-resources/>



Palliative Care in Queensland Requirements for New Investment to Transform Care

November 2020
palliativecareqld.org.au

What does a purpose-built palliative care system for all Queenslanders look like?

Palliative care is a recognised human right, which provides a holistic approach to improving the quality of life for terminally-ill people at all stages of life - from in utero to geriatric - that should be available from the day of diagnosis until death and beyond to bereavement support for loved ones.

Though many Queenslanders receive timely and high-quality palliative care, this care is not available to all. At present, access to palliative care for Queenslanders is a lottery based on where they live, their age, their illness, their culture and even the way their local Hospital and Health Service allocates its funding.

To address the critical shortages and gaps in palliative care for Queenslanders, Palliative Care Queensland, as the sector's peak body, is proposing new investment to create a purpose-built palliative care system that provides timely and high-quality care when and where Queenslanders need it.

This request for funding has been created together with AMA Queensland and representatives from the Queensland Specialist Palliative Care Medical Directors' Group as well as through regular consultation with communities from across the state. As a result, this funding request is truly representative of the needs of all Queenslanders from specialist health practitioners to carers of those approaching their end of life.

This funding proposal seeks to address the significant system challenges faced by the palliative care sector in Queensland. These challenges are identified by Reports No. 33 and 34, 56th Parliament – Inquiry into aged care, end-of-life and palliative care and voluntary assisted dying¹.

In response, the Queensland Government has committed to increasing investment for the delivery of palliative care². To bring about this system transformation, we propose that Queenslanders need \$385 Million per year of dedicated funding to palliative care.

Currently, palliative care receives only \$110 Million per year in funding. The current state budget supporting the delivery of palliative care to the Queensland community makes up less than 1% of the total annual state health budget of approximately \$19 billion dollars, yet palliative care is universal, touching all Queenslanders directly and indirectly. This is grossly inadequate to meet the care needs of dying Queenslanders, their carers, families and front-line medical professionals upon which the sector relies.

Palliative Care Queensland proposes an additional investment of \$275 Million with a two-pronged approach to new funding:

- The first prong focuses on improving palliative care health service delivery (with new investment of \$241 Million per year)
- The second prong builds community capacity (with new investment of \$34 Million per year)

The proposed investment provides a roadmap for systematic, positive and balanced transformation of palliative care for all, directly improving the quality of life for terminally-ill Queenslanders at all stages of life - from in utero to geriatric.

An increase in funding of \$275 million per annum, equates to less than \$53 per capita per annum³, a small investment to meet a universal need and address a human right.

¹ Queensland Parliament (2020). Reports No. 33 and 34, 56th Parliament - Inquiry into aged care, end-of-life and palliative care and voluntary assisted dying. Retrieved 30 September 2020. <https://www.parliament.qld.gov.au/work-of-committees/committees/HCDSDVPC/inquiries/past-inquiries/AgedCareEOLPC>

² Queensland Government (2020). Queensland Government Response Health, Communities, Disability Services and Domestic and Family Violence Prevention Committee Report No. 33: Aged care, end-of-life and palliative care. Retrieved 30 September. <https://www.parliament.qld.gov.au/Documents/TableOffice/TabledPapers/2020/5620T1686.pdf>

³ \$275 million divided by 5,160,023 persons. Queensland's preliminary ERP as at 31 March 2020 - Queensland Treasury <https://www.qgso.qld.gov.au/statistics/theme/population/population-estimates/state-territories>

Funding: Prong 1

What are we investing in?	Palliative Care Service Delivery	
What does this mean for every Queenslanders?	Care for you and your support network when and where you need it	
New investment required?	\$241 Million per year	
What new investment is needed per year?	Summary	Details (inc. amount per year)
Palliative Home Care Packages (Flexible funding packages) <i>Total: \$117 Million</i>	Last Days Packages: Provide flexible funding coordinated by the local specialist palliative care service to fund additional nursing care needs during their terminal care phase	10,000 packages/year: \$70 Million
	Palliative Care Community Packages: Provide flexible funding coordinated by the local specialist palliative care service for the last 6 months of life and to support the transition of children with palliative needs to adult care	14,000 packages/year: \$42 Million
	MASS Statewide palliative care patient equipment and syringe driver program: Provide essential equipment supplies to people's homes in a timely manner for the last 6 months of life	\$5 Million
Specialist palliative care workforce <i>Total: \$72 Million</i>	Palliative Medicine Physicians including Consultants, Registrars & Resident Medical Officers	40 FTE: \$20 Million
	Palliative Care Nursing Specialist workforce including Nurse Practitioners, Clinical Nurse Consultants & Clinical Nurses	130 FTE: \$25 Million
	Palliative Care Allied Health Specialist workforce including bereavement counsellors & spiritual care coordinators	65 FTE: \$10 Million
	Palliative Care Administrative Support Staff including volunteer coordinators	40 FTE: \$5 Million
	Palliative Care Clinical Educators	35 FTE: \$7 Million
	Advance Care Planning Facilitators	25 FTE: \$5 Million
Targeted Palliative Care Service Delivery Programs <i>Total: \$50 Million</i>	First Nations Palliative Support: Statewide specialist palliative care support and a Centre for Excellence	\$9.5 Million
	Hospice and Specialist NGO Support Program: Hospice and Specialist NGO specialist support and care model expansion	\$10 Million
	SPARTA (Queensland's Specialist Palliative Rural Telehealth Service): Regional, rural and remote hub and spoke support and education	\$5 Million
	PallConsult: Statewide specialist medical, nursing and allied health telephone support for adult generalist and primary care providers	\$2 Million
	Office of Advance Care Planning: Statewide Advance Care Planning information, support and tracking service	\$1 Million
	Statewide Paediatric Palliative Care Collaborative Outreach Service: Expand children's services to include telehealth outreach and a 24-hour paediatric support phone line	\$2 Million
	Aged Care Palliative Support: Provide specialist palliative care support and consultation services for residential and community aged care	\$12.5 Million
	Statewide Bereavement Support Program: Counselling services, bereavement support groups and telephone advice for generalist services	\$5 Million
Technology investment <i>Total: \$2 Million</i>	ICT: Investment in technology solutions to complement service delivery and enable increased access to palliative care services 'in the home' or 'close to home' (particularly to regional, rural and remote clients)	\$2 Million

Funding: Prong 2

What are we investing in?	Palliative Care Capacity Building	
What does this mean for every Queenslander?	Your community and services are equipped to care for Queenslanders experiencing life-limiting diagnoses, dying, death and grief. Queensland is a compassionate community where palliative care is everyone's business.	
New investment required?	\$34 Million	
What new investment is needed per year?	Summary	Details (inc. amount per year)
Specialist Palliative Care Training and workforce development programs <i>Total: \$13 Million</i>	Specialist Palliative Medicine Training and Support program	25 places \$5.5 Million
	Specialist Palliative Care Nursing Training and Support program	40 places \$5 Million
	Specialist Palliative Care Allied Health Training and Support program	20 places \$2.5 Million
Invest in Workforce, Research, Quality Improvement and Innovation <i>Total: \$11 Million</i>	Palliative Care Database Registry: A Queensland fit for purpose data registry system which builds profiles of palliative care teams, operations and service delivery as well as mapping service delivery. This registry will also share progress measures, tracking capacity and reach, ultimately providing a statewide report card for palliative care	\$8 Million
	Centre for Palliative Care Research and Education: Including research grants, fellowships and scholarship funding	\$3 Million
Policy, Engagement, Awareness Raising and Last Wishes <i>Total: \$1 Million</i>	Palliative Care Queensland: Provide advice regarding palliative care strategy and policy issues. Ongoing engagement and consultation with stakeholder groups and community awareness initiatives for National Palliative Care Week & World Hospice and Palliative Care Day	\$600,000
	Ambulance Wish Queensland: Establishment of 3 sites across Queensland, expanding reach to the regional areas	\$400,000
Community Capacity Building, Engagement and Development <i>Total: \$9 Million</i>	Statewide Palliative Care Volunteering Program: A statewide 'Volunteer Village' to support palliative care services (specialist and generalist) and community groups, based on existing programs in NSW, VIC and ACT	\$4 Million
	Queensland Compassionate Communities: Build community capacity through community development, engagement and awareness initiatives, including community education, community signposting and community support for underserved populations (including homeless, diverse population groups and prisoners). This approach utilises Public Health Palliative Care models.	\$5 Million



Palliative Care Queensland (PCQ) is the peak body for palliative care in Queensland. PCQ has been operating for over 30 years, has over 300 members and is a founding member of Palliative Care Australia. PCQ members include health professionals across all sectors of health, specialist and generalist palliative care services, aged care, disability care, peak bodies, as well as consumers and interested members of the Queensland community. Collectively, the PCQ membership body holds tremendous knowledge about the challenges the sector faces and the opportunities those challenges can bring.

Our organisational priorities are that all Queenslanders:

- are able to live every day until their last
- are able to have a dignified death, regardless of their illness, age, culture or location
- have access to a supportive social network at the end phase of life and have the choice of quality palliative care

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