**Attn:**
Dr Tanzil Rahman
Chair,
Legal and Constitutional Affairs Committee
Legislative Assembly Northern Territory

Palliative Care Australia
Matters of life and death

Dear Dr Rahman

Thank you for seeking input from Palliative Care Australia (PCA) on your Consultation Paper – Voluntary Assisted Dying in the Northern Territory July 2025.

PCA commends the Northern Territory (NT) Government on a clear and succinct consultation paper on the possible introduction of Voluntary Assisted Dying (VAD) in the NT.

PCA has attached two documents: our *Palliative Care and Voluntary Assisted Dying Position Statement* and *Voluntary Assisted Dying in Australia - Guiding Principles for those providing care to people living with a life-limiting illness*. These documents contain key messages that PCA would convey in response to your consultation paper, most importantly:

- If palliative care health professionals or organisations choose to offer and provide VAD for their patients with life-limiting illness, this is a practice separate from palliative care. However, people may choose to receive palliative care throughout the VAD process.
- In Australia, an individual's choice to explore VAD 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. Every Australian 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 care if required.
- Palliative care is person and family-centred care with the goals of ensuring patient psychological safety and optimising quality of life. Palliative care helps people live their life as fully and comfortably as possible when living with a life-limiting illness.
- 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, does not constitute VAD.

In addition to this, PCA would like to share what it has learned through its networks in jurisdictions where VAD has been implemented. This is summarised below and may be useful to your consideration in developing legislation, policies, and services for a VAD service in the NT:

- Many palliative care clinicians and services work in or with VAD processes. Recent annual reports from jurisdictions show around 80 per cent of people seeking VAD are, or have been, receiving palliative care. In other words, there is a strong overlap between the clinicians providing VAD services and palliative care clinicians; likewise, there is a strong overlap between the population of patients receiving palliative care and those seeking VAD.
- All jurisdictions should provide access to palliative care to people who have a life limiting illness, but for many in remote and regional communities, access to palliative care is often limited due to reduced health services. PCA continues to call for greater investment in palliative care services.
- The NT should implement a community awareness campaign of at least 2 years duration, promoting an understanding of what palliative care is and what support it can provide. Community understanding of palliative care is important in the context of the introduction of VAD.
- PCA notes that all jurisdictions except the NT, have developed a palliative care or end-of-Life framework to underpin their services in accordance with the National Palliative Care Strategy 2018. PCA would encourage the NT to work with its non-government palliative care sector, including Palliative Care Northern Territory, to develop and articulate how it will provide these services to its citizens.
- Currently the use of telehealth for the purposes of VAD is deemed criminal by Commonwealth law; this is identified as a barrier in most jurisdictions and by other health professional organisations. The effective ban on discussing VAD as an end-of-life choice over a “carriage service” and the requirement for face-to-face consultation only, has without doubt impacted access to VAD, especially in some regional and more remote communities. Providing timely and equitable access to VAD regardless of location is a challenge that the NT Legislative Assembly will need to address if it decides to implement VAD.
- The creation of a safe environment for clinicians and services who conscientiously object to VAD is important to a sound VAD process. A safe environment will reduce negative impact on a patient’s access to palliative care, without limiting their access to information about choices regarding VAD.
- Introducing a new service requires the existing workforce to learn and adapt. There must be investment in building understanding of palliative care and VAD in your broader health workforce through regular education and support mechanisms. Introducing VAD requires

health system and cultural change in the workplace. It is important to provide resources for a period of time for this support.

- Similarly, the general community need information about pathways to healthcare and other support for people with life limiting illness and conditions. Again, introducing VAD is a cultural shift within the community. Providing appropriate information and support for its introduction and operation is an investment the NT must make for an effective VAD service. One example of a service where there is positive feedback, is the Queensland Voluntary Assisted Dying Support Service (QVAD-Support), which provides advice and support to Queenslanders about voluntary assisted dying. QVAD-Support is staffed by care coordinators who are medical, nursing, and allied health professionals, and provides support to anyone involved with voluntary assisted dying in Queensland, including, people who want to access VAD, carers and family members of people wanting to access VAD, healthcare workers and healthcare providers.
- As noted in the consultation paper, there are learnings for the NT to considered from the previous experience with The ROTI Act and from other jurisdiction's VAD systems on providing culturally safe services. It is important to provide information, support, and services to people in culturally appropriate ways. For many Aboriginal and/or Torres Strait Islander peoples the very location of VAD services may inhibit their willingness to access hospital and health services. In some communities, clinicians have expressed that co-located health and VAD services may incite fears of colonial genocide in their clients. PCA supports Recommendation *6 of the Report into Voluntary Assisted Dying in the Northern Territory 2024*, which seeks the resourced development of a process to address Aboriginal and Torres Strait Islander cultural safety in a VAD process. PCA would also recommend a co-designed approach to its development. Further PCA supports the establishment of a stand-alone VAD service, in the NT to protect the cultural safety of palliative care services, as recommended by the *Report into Voluntary Assisted Dying in the Northern Territory 2024*, and Palliative Care Northern Territory.

Thank you again for providing Palliative Care Australia the opportunity to contribute to your consultation process.

Yours sincerely

[redacted]

Camilla Rowland
Chief Executive Officer
Palliative Care Australia
14 August 2025

POSITION STATEMENT

# Palliative Care and Voluntary Assisted Dying

**Palliative care** is an approach that improves the quality of life of patients and their families facing the problems associated with life-limiting 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.[1]

**Voluntary assisted dying (VAD)** refers to the assistance provided to a person by a health practitioner to end their life. The term 'voluntary assisted dying' evolved in Australia in recent years following inquiries and parliamentary debates of laws enabling a terminally ill person to seek medical assistance to die. This term is now commonly used in Australia, rather than euthanasia or physician-assisted suicide or dying. It includes:

- 'self-administration', where the person takes the VAD medication themselves, and
- 'practitioner administration', where the person is given the medication by a doctor (or in some Australian States, a nurse practitioner or registered nurse).

'Voluntary' indicates that the practice is a voluntary choice of the person, and that they are competent (have capacity) to decide to access VAD.[2]

Voluntary assisted dying laws have been enacted in all Australian states and will be operational in all states by end of 2023. Palliative Care Australia (PCA) recognises that the topic of voluntary assisted dying raises difficult and complex ethical issues, and that there is a broad spectrum of opinion on, and support or opposition to, VAD within the Australian community. PCA represents health professionals, carers and consumers, and notes that this diversity of opinion is also reflected within the palliative care community. With an ageing population and rising chronic illness, Australia needs greater investment in palliative care and more support for the workforce that cares for people toward the end of their life.

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[1] Australian Government Department of Health (2018) p. 42 *National Palliative Care Strategy 2018,* Department of Health and Aged Care Website, accessed 1 July 2022.

[2] Australian Centre for Health Law Research Queensland University of Technology, *Voluntary Assisted Dying* , QUT End of Life Law in Australia Website, accessed 1 July 2022.

### The difference between palliative care and voluntary assisted dying

It is important to recognise the difference between palliative care and VAD.

PCA believes that:

- If palliative care health professionals or organisations choose to offer and provide VAD for their patients with life-limiting illness, this is a practice separate from palliative care. However, people may choose to receive palliative care throughout the VAD process.

- In Australia, an individual's choice to explore VAD 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.[3] Every Australian 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 care[4] if required.

- Palliative care is person and family-centred care with the goals of ensuring patient psychological safety and optimising quality of life. Palliative care helps people live their life as fully and comfortably as possible when living with a life-limiting illness.

- 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, does not constitute VAD.

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

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

- 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 VAD.

- It is the right of health professionals providing palliative care to make appropriate judgements about whether they will be involved in VAD based on their personal ethics and beliefs and the policies of their employer/s.

- All people working in palliative care should be treated respectfully and demonstrate professional behaviour towards colleagues and co-workers regardless of their views on VAD, and regardless of any decision to exercise their right to conscientiously object to or conscientiously participate in any aspect of VAD.

PCA 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

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[3] World Health Organization (2018) *Palliative care fact sheet*, WHO Website, accessed 1 July 2022.

[4] Specialist palliative care is delivered by 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*, Palliative Care Australia Website, accessed 1 July 2022.

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. PCA recommends that the *Guiding Principles* be referred to alongside relevant legislation, organisational policies and codes of conduct.

## Considerations for end of life and VAD legislation, guidelines and review processes

Where voluntary assisted dying is legally available to people, governments 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 their needs, hopes and care preferences consistent with their personal values, culture, beliefs and goals. Patients should be advised of the palliative care options available to them.

- Health professionals have the right to conscientiously object, and should be protected from participating in the VAD process if they so choose.

- Any legislation, guidelines or review process should promote high-quality care and ensure patient safety. This includes ensuring patients will receive continuity of care across settings and throughout the course of their illness.

- Governments should invest in research including data collection related to VAD to enable its ongoing review, to monitor safe practice, and to assess the impacts of VAD on patients, their families, their carers and personal supporters. In addition, research is needed on the impact (including the cultural impact) of VAD on the health workforce.

## Further investment is required to meet Australia’s palliative care needs

Greater investment is required at national, state and territory levels to ensure that the systems and people are available to provide quality palliative care where and when it is needed.[5] There is significant unmet need for palliative care in Australia and forecasts indicate further increases in need in the years ahead.[6]

PCA calls for:

- Substantial coordinated investment by all jurisdictions to plan and prepare for a future where Australians will live longer, demand an improved quality of life, and require access to high quality palliative care when living with a life-limiting illness.

- Investment in growing the specialist palliative care workforce, and increased support for the acute, primary care and the aged care sectors to provide quality palliative care as part of their core business.

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[5] Australian Government Department of Health, p. 20 *National Palliative Care Strategy 2018*, accessed 1 July 2022.

[6] Australian Government Productivity Commission, *Introducing Competition and informed User Choice into Human Services: Reforms to Human Services*, No.85, 27 October 2017, accessed 1 July 2022.

- Palliative care to be included as a core component of all health and aged care quality standards.

- The difference between palliative care and voluntary assisted dying to be made clear wherever possible, supported by a fully resourced and sustained national public awareness campaign about palliative care, what it offers and how and when it can be accessed.

- Allowance for healthcare professionals to have time to access clinical and/or professional supervision and self-care support, noting that healthcare professionals can experience high levels of distress when involved with the process of VAD .

- Integration of palliative care programs into public health care policies, with ongoing evaluation of coverage, equity and accessibility while developing comprehensive programs.

- Further investment in training and education:
    - Training in advanced communication skills that promote respectful dialogue in end-of-life and advance care planning discussions with people. 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 and consistent palliative care education and training for all medical, nursing, allied health and pharmacy students as part of undergraduate curricula including clinical, legal, and ethical considerations. This will 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.
    - Ongoing, consistent education, training and refresher courses to health clinicians currently employed in the health sector.
    - Periodic review of cultural competency training curricula for care staff working at Residential Aged Care Facilities (RACFs), to ensure the cultural and religious needs of people from diverse cultural backgrounds at the end of life are adequately included.
    - Review of current vocational education and training courses such as the Certificate III and IV in Aged Care, Ageing Support, Diploma of Nursing and other occupations sets or courses that are considered as a minimum qualification to provide direct and indirect services to older residents at RACFs. This is to ensure that the staff involved in providing direct and indirect care to older adults at the end of life are current in their knowledge of palliative care.

# Voluntary Assisted Dying in Australia

## Guiding principles for those providing care to people living with a life-limiting illness

### WHY ARE THESE PRINCIPLES NECESSARY?

Palliative Care Australia (PCA) acknowledges that voluntary assisted dying (VAD) laws have been enacted in all Australian states and will be operational in all states by the end of 2023. Voluntary assisted dying poses 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.

PCA proposes seven guiding principles, of equal importance, to sit alongside legislation (if applicable), organisational policies and/or professional codes of conduct. Underpinning these principles are the following 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 family[1] and carers.
- Dying is a normal part of life and 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, and often involves psychological distress and existential concerns that must be explored appropriately.
- Grief is the normal emotional reaction to loss, but the course and consequences of bereavement will vary for each individual. Palliative care integrates the psychological, spiritual and cultural aspects of care, and offers a support system to help carers and families cope during the person’s illness and in bereavement.

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[1] The term *family* includes people identified by the person as family. This may include people who are biologically related and/or those who are not. People who joined the family through marriage or other relationships, such as kinship, as well as the chosen family, street family (for those experiencing homelessness), and friends (including pets) may be identified by the person as family. A person may also choose to not to have their family or carers involved in their care, or a person may not have any family or carers.

## 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.

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 care[2] team members including palliative care physicians, nurse practitioners, palliative care nurses, specialist allied health professionals, grief and bereavement counsellors and spiritual/ 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

### 1. People living with a life-limiting illness are supported and respected as they explore their options and make end-of-life care decisions which may include 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 options available to them, which may include VAD where this is legally[3] available to them based on eligibility criteria. 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:

- 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 is 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. Likewise, a person with a life-limiting illness may have specific family members or friends they wish to exclude from end-of-life decision making, treatment and care.

### 2. People exploring voluntary assisted dying are not 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, VAD. A person living with a life-limiting illness, their family and carers should not be made to feel judged, abandoned, or scared that care will be adversely affected if they want to explore VAD.

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[2] Specialist palliative care is delivered by 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*, Palliative Care Australia Website, accessed 1 July 2022.

[3] Within the parameters of respective legislative requirements related to initiating discussions and providing information about VAD.

Health professionals, care workers and volunteers should:

- Advise a person with a life-limiting illness that palliative care is always available even if they are considering VAD.
- 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".[4]
- 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 options.
- Communicate appropriately, including across multiple teams or multiple health or aged care organisations and locations. Ongoing discussion and consultation at various points along the treatment continuum is paramount.
- Ensure people living with a life-limiting illness do not have undue delays in accessing VAD when health professionals/providers/services exercise the right to conscientious objection.
- Consider when referral to specialist palliative care would assist when there are more complex and persistent needs.

### 3. Respectful and professional behaviour is displayed 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 VAD 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 and scope of practice, whilst continuing to provide safe, high quality and 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 VAD.
- Advocate for system measures to facilitate the provision of information about, or access to voluntary assisted dying, regardless of conscientious objection, to ensure autonomy and continuity of care for the person living with a life-limiting illness.
- Have their privacy and confidentiality respected and maintained.

### 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 VAD is raised, involves both giving and receiving information at a time where heightened 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:

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[4] World Health Organization (2018) *Palliative care fact sheet*, WHO Website, accessed 1 July 2022.

- Be provided with professional development in soft communication skills particularly focused on understanding grief and culturally appropriate communication.
- Be given the time to prepare for and have respectful and compassionate discussions.
- Ensure any individual requesting information on, or access to, VAD feels supported during all conversations.

### 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 ongoing multidisciplinary 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:

- Focus on the emerging need for a streamlined patient-centred system for referrals between palliative care and VAD services.
- Be aware of their own training and education needs, particularly in relation to having conversations with people about end-of-life, pain and other symptom management, recognising deterioration, grief and bereavement, and self-care.
- Be supported to prioritise self-awareness and self-care strategies that include both physical and emotional health, and to actively manage distress. This will include accessing clinical/professional supervision.
- 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 VAD.[5]

### 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. Training and guidance in managing emotionally challenging situations must be backed up by organisational policies and processes that identify and support those at risk of moral distress 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/clinical supervision and mentoring.
- Be supported when involvement with any aspect of VAD 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

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5 A free training resources for clinicians is available through QUT End of Life Law for Clinicians online training, including modules on VAD and the role of law in end-of-life care https://palliativecareeducation.com.au/course/index.php?categoryid=5

participate in any aspect of VAD dying, and regardless of whether they work in an organisation/service that provides access to VAD.

### 7. Continuous learning from evidence and evolving practice is vital to drive quality improvement in voluntary assisted dying

The evidence base, legal requirements and policy frameworks related to VAD 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 VAD to enable review of any scheme, 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 VAD.
- Advocate for transparent public reporting on VAD as a mechanism to improve patient safety and choice.
- Be aware of the emerging interface between palliative care and VAD, and work to ease the navigation between systems for people with life-limiting illness.

**Palliative care** is an approach that improves the quality of life of patients and their families facing the problems associated with life-limiting 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[6]

**Voluntary assisted dying (VAD)** refers to the assistance provided to a person by a health practitioner to end their life. The term 'voluntary assisted dying' evolved in Australia in recent years following inquiries and parliamentary debates of laws enabling a terminally ill person to seek medical assistance to die. This term is now commonly used in Australia, rather than euthanasia or physician-assisted suicide or dying. It includes:

- 'self-administration', where the person takes the VAD medication themselves, and
- 'practitioner administration', where the person is given the medication by a doctor (or in some Australian States, a nurse practitioner or registered nurse).

‘Voluntary’ indicates that the practice is a voluntary choice of the person, and that they are competent (have capacity) to decide to access VAD.[7]

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[6] Australian Government Department of Health (2018) p. 42 *National Palliative Care Strategy 2018*, Department of Health and Aged Care Website, accessed 1 July 2022.

[7] Australian Centre for Health Law Research Queensland University of Technology, Voluntary Assisted Dying , QUT End of Life Law in Australia Website, accessed 1 July 2022.