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 family¹ 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.

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.

Palliative Care Australia is the national peak body for palliative care in Australia. PCA provides leadership on palliative care policy and community engagement. Working closely with consumers, its Member Organisations and the palliative care and broader health workforce, PCA aims to improve the quality of life and death for people with a life-limiting illness, their families and 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 care² 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 legally³ 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 lifelimiting 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.

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:

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

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 <u>https://palliativecareeducation.com.au/course/index.php?categoryid=5</u>

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 spiritual⁶

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

⁶ Australian Government Department of Health (2018) p. 42 <u>National Palliative Care Strategy 2018</u>, Department of Health and Aged Care Website, accessed 1 July 2022.

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