

Voluntary Assisted Dying in Australia

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



PalliativeCare
AUSTRALIA

Why are these principles necessary?

Palliative Care Australia (PCA) acknowledges that where introduced or being considered, legislation within Australian jurisdictions that legalises voluntary assisted dying¹ 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 family² 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, 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 care³ team members including palliative care physicians, nurse practitioners, palliative care nurses, specialist allied health, grief and bereavement counsellors, 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.

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1. 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.

2. Family includes self-designated family

3. 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].

The guiding principles

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 legally⁴ 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:

- 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.

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”.⁵
- 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.

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.
- Advocate for system measures to facilitate the provision of information about, or access to voluntary assisted dying, regardless of conscientious objection to ensure continuity of care for the person living with a life-limiting illness.
- Have their privacy and confidentiality maintained.

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.

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

5. 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

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.

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.
- 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.

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.

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, 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.

 **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.

Palliative Care Australia

P: 02 6232 0700

E: pca@palliativecare.org.au

www.palliativecare.org.au

Unit 8, 113 Canberra Avenue
Griffith ACT 2603

PO Box 124
Fyshwick ACT 2609



PalliativeCare
AUSTRALIA