



## POSITION STATEMENT

### End-of-life Care

#### Position

End-of-life care is the healthcare that people receive in the last years, months and weeks of their lives. It includes palliative care and care provided in the last days of life, including voluntary assisted dying. Provision of quality, compassionate end-of-life care can minimise the distress and grief associated with death and dying for the individual, and for their family, friends and carers.

End-of-life care should be provided by interdisciplinary team members working together; with recognition of and respect for the patient's wishes, their cultural or spiritual practices; and in coordination with family members or carers. Pharmacists are essential members of end-of-life care interdisciplinary teams.

Australia's aging population, constraints on hospital, hospice and residential care beds, and patient preferences are leading to an increase in the number of people choosing to die at home. Community pharmacists are increasingly involved in the responsible and compassionate provision of end-of-life care.

The Pharmacy Guild of Australia (the Guild) supports policies and practice principles that:

- Are patient and family-centred; are provided with dignity, respect and compassion; and are aligned, as far as possible, with the values, needs and wishes of the individual, and their family or carers.
- Recognise the cultural, spiritual and psychosocial needs of patients, and their families and carers.
- Preserve independence, maintain quality of life and provide patients with a choice of available evidence-based treatment options.
- Ease pain and relieve other distressing symptoms.
- Support people requiring palliative care to live independently in the community for as long as possible, before needing to move to specialised facilities.
- Reduce admissions to hospital or poor health outcomes due to medicine management issues.

#### Principles of care provision

Decisions about care delivered at end-of-life should be guided by the wishes of the patient and any advanced care planning documentation. Health professionals should understand the laws and principles of advance care planning<sup>1</sup> and end of life care, including for older Australians<sup>2</sup>. End-of-life care should be coordinated with the patient's full health care team, including general practitioner, specialist physicians, other healthcare providers and family members and carers.

Effective communication between community pharmacists and general practitioners and other prescribers such as nurse practitioners ensures the best patient outcomes and avoids unnecessary delays in supply of medication.

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More frequent review of a person's medication management requirements may be necessary to respond to sudden changes in the patient's health status or to manage any issues with the provision of health services. This includes consideration of prescribing new medications, deprescribing medications that are no longer of benefit or even managing medicine supply disruptions, all of which pharmacists play a role.

## **Palliative care**

Palliative care is a care approach that aims to improve quality of life by relieving pain, distressing symptoms and suffering of patients facing a life-limiting condition. The Guild believes that palliative care is a fundamental element of end-of-life care, recognising that long-term palliative care services may be required for some life-limiting conditions. The Guild supports continued investment in palliative care services to improve availability, access and service quality, and to provide patients with choices regarding their end-of-life care.

The quality of palliative care is improved when patients are treated by a healthcare team comprised of a variety of health professionals each with their own knowledge, skills and experience. Palliative care should be planned and delivered with consideration for the person's psychosocial, spiritual, cultural and emotional needs.

The role of community pharmacists in interdisciplinary palliative care teams should be recognised. Pharmacists can contribute to the management and care of patients through:

- Responsible and timely provision of medicines to relieve pain and symptoms.
- Review of prescription and non-prescription medicines, and recommendations on deprescribing.
- Advice on adjustment to dose forms, for example in response to swallowing difficulties.
- Advice on aids to assist with medication adherence.
- Advice on the management of adverse effects of medicines, such as constipation, dry mouth, sedation, insomnia.

Palliative care may be provided for years from initial diagnosis and pharmacists may and should be involved in provision of care for a long time. It is recommended that people with a life-limiting condition be linked in with a palliative care service sooner rather than later. However, stigma and misunderstanding mean too many people access it far too late and may suffer as a result.

Greater involvement of pharmacists in palliative care teams can improve the quality of care and quality of life of patients who require palliative care and allow patients to remain in their home for longer. Community pharmacists can reduce admissions to hospital, whether due to poor symptom control, adverse effects of medications, or medicine related problems from inappropriate polypharmacy. The provision of high-quality care in the home environment reduces reliance on hospices and residential care facilities.

Funding should be provided to involve community pharmacists in Comprehensive Care Plan arrangements for patients requiring palliative care. This is currently not the case and pharmacists are often invited to be part of these team care arrangements without remuneration.

## **Last days of life**

Terminal care is healthcare provided to patients who are anticipated to die within a matter of hours, days or occasionally weeks. During this phase, management of the patient's symptoms is paramount, and the timely and appropriate management of medicines can allow patients to remain at home with their families through the dying process. Appropriate management of symptoms during the patient's final stages of life reduces distress for both the patient and their family.

To ensure community pharmacies are able to provide the highest quality care it is appropriate for community pharmacies to be included in the terminal care planning for a person and to be appropriately remunerated for the services provided.

#### ***Timely provision of medicines***

Community pharmacies should be recognised and appropriately reimbursed for the timely supply of core medicines used in the terminal phase of life, which may not be commonly used otherwise. Expenses incurred by community pharmacies can include holding and storing infrequently used medicines for urgent requests, after-hours (on-call) service costs and home delivery costs.

Funding schemes should recognise the short-term, speciality storage and dispensing of medicines for end-of-life care and management of terminal symptoms is not typical of many other pharmaceutical benefits, particularly for community pharmacies that are not specifically contracted to provide end of life services.

Medicine funding schemes, including the Pharmaceutical Benefits Scheme (PBS), must ensure that pharmacists are reimbursed for the *bona fide* and good faith supply of all medicines dispensed for a patient for palliative care or end-of-life management. This includes situations when a claim is made for a medicine supplied on authorisation by a prescriber (e.g. via a valid telephone order) and given to a patient prior to their death, but a prescription is provided by the prescriber after the date of the patient's death. Laws and claim management systems should allow for the payment of claims in these instances.

#### **Voluntary assisted dying**

In some circumstances, a person may choose to access a voluntary assisted dying (VAD) service. It is appropriate that some community pharmacies may choose to provide VAD services where this is allowed by state or territory legislation and procedures. The Guild believes that there is opportunity for this service to be provided from community pharmacy, if proprietors and pharmacists are willing to provide the service. Community pharmacists are responsible custodians of medicines for their communities and their potential involvement in end-of-life care, including voluntary assisted dying, is reflective of the full scope of practice of community pharmacists.

As VAD is regulated by state and territory laws, proprietors and pharmacists must check the legislation of the state or territory in which the pharmacy is located before providing any advice or services relating to VAD. Information regarding eligibility criteria and access to a VAD service is provided on the websites of the health department of each state or territory.

The competence of community pharmacists to dispense VAD medicines professionally and compassionately for their patients should be recognised in the design, implementation, or review of VAD healthcare services. Involving community pharmacists in VAD service design may increase the accessibility of the service in rural and remote areas.

The Guild expects community pharmacies involved in VAD services to have the appropriate clinical governance and quality assurance arrangements in place to ensure the safe, confidential and professional provision of VAD services.

#### ***Right to refuse to provide voluntary assisted dying advice or service***

The legalisation of VAD may present an ethical or social challenge for some pharmacists who may have an objection to the supply of medicines used to end the life of a terminally ill patient. The Guild respects

and supports the rights of pharmacy owners and individual pharmacists who conscientiously object to voluntary assisted dying to refuse to participate in requests for, or processes of, a VAD service.

The right to refuse to dispense VAD substances is enshrined in state legislation, however some states require healthcare practitioners who have a conscientious objection to voluntary assisted dying to refer patients to other healthcare services for information.<sup>3</sup>

The personal freedom for pharmacists to refuse to supply substances used for voluntary assisted dying must be preserved, and pharmacists must be protected from victimisation for their choice. The Guild believes pharmacists are entitled to keep private the reasons for their decision.

VAD legislation, including any future amendments, must contain protections for health professionals who conscientiously object to voluntary assisted dying. VAD legislation and regulations, and the mechanisms that facilitate the operation of this legislation, should not publicly identify whether community pharmacies are, or are not, dispensing voluntary assisted dying medicines.<sup>4</sup>

#### ***Protection for pharmacists who provide voluntary assisted dying advice or service***

VAD laws must not inadvertently lead to pharmacists facing disciplinary action resulting from a decision to dispense, or to not dispense, a VAD substance. As the representative organisation for community pharmacy, the Guild must be consulted on the development of VAD legislation or amendments, to ensure the protection of community pharmacists who may be involved in VAD services.

VAD legislation and associated regulations must clearly define the responsibilities of a proprietor pharmacist who operates community pharmacies across different jurisdictions. It is the Guild's view that a pharmacist who resides in a jurisdiction that has not legalised VAD but who owns a pharmacy in a jurisdiction that has legalised VAD should be protected, under state of residence laws or other legislation, for actions performed in a state where VAD is legal.

Proprietors and pharmacists should be aware of the requirements and potential consequences of VAD regulations in the state or territory in which their pharmacy is located, in particular regard to advice provided about accessing VAD. For example, the Victorian *Voluntary Assisted Dying Act 2017* makes it an offence punishable by life imprisonment for any health practitioner to raise the option of voluntary assisted death before the patient raises it themselves.

If a patient or family member asks a pharmacist about VAD, the pharmacist should refer them to their general practitioner or to another medical specialist involved in the person's care.

## **Background**

Pharmacists are experts in medication use and are responsible custodians of medicines. Community pharmacists have appropriate competencies and skills to dispense medications and provide services and support for end-of-life care. End-of-life care should be provided by community pharmacists in accordance with the requirements of relevant legislation, *Professional Practice Standards*<sup>5</sup>, the Ahpra *Shared Code of Conduct*<sup>6</sup>, and requirements of the *Quality Care Community Pharmacy Standard AS:85000:2017*.

The Australian Commission on Safety and Quality in Health Care has also published a *National Consensus Statement: Essential elements for safe and high-quality end-of-life care*<sup>7</sup>.

## **Medication Supply and End of Life Care**

Many medicines used in palliative care and terminal care are listed on the PBS including many items with a specific palliative care listing.<sup>8</sup> The use of multiple medicines, and of higher doses of medicines, is common during the last days of life.

State and territory health departments have regulations and requirements in place to manage the over-use or inappropriate prescribing and dispensing of Controlled Drugs. However, such requirements generally do not apply to the prescribing and dispensing of Controlled Drugs for palliative care patients, especially during the last days of life. Legal protection is provided to practitioners for the prescription of medication for pain and symptom relief in palliative care.<sup>9</sup>

The Brisbane South Palliative Care Collaborative has produced a *Guide to the Pharmacological Management of End of Life (Terminal) Symptoms in Residential Aged Care Residents* as a guide for health professionals working in residential aged care<sup>10</sup>.

## **Advanced Care Planning**

An advance care plan (or advance care directive) is a written document that allows an adult to record their preferences for future medical treatment, should they lose decision-making capacity. An advance care plan may record general statements about the person's values and preferences to guide future medical treatment decisions, or record instructions consenting to or refusing specific types of treatment. A plan may appoint a substitute decision-maker to make decisions about health care and personal life management. Advance care plans are recognised by common law, and/or specific legislation.

Details of a patient's advance care plan may be documented in their My Health Record. Alternatively, the patient, or their authorised representative, may share this document as necessary. Advance care plans are a valuable resource for health professionals to ensure that patients receive care according to their wishes.

## **Voluntary assisted dying legislation**

Laws that allow VAD have been passed in most Australian jurisdictions, with some differences in legislation and requirements between states. At the time of writing this position statement, VAD is not legal in the Northern Territory or the Australian Capital Territory.

A summary of the current status of VAD, including eligibility criteria is maintained by the Queensland University of Technology<sup>11</sup>.

## **Authority**

### **Endorsed**

*End-of-life care*

National Council – December 2023

*Voluntary Assisted Dying*

National Council – March 2018

### **Reviewed**

Policy and Regulation Sub-Committee – July 2023

Policy and Regulation Sub-Committee – March 2018

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## References

<sup>1</sup> [Advance Care Planning Australia](#)

<sup>2</sup> [www.eldac.com.au](http://www.eldac.com.au)

<sup>3</sup> End of Life Law in Australia, Queensland University of Technology, <https://end-of-life.qut.edu.au/assisteddying>

<sup>4</sup> The Guild acknowledges there will be a need for health departments to maintain a secure and confidential database of pharmacies involved in the provision of voluntary assisted dying medicines.

<sup>5</sup> [Professional Practice Standards | Pharmaceutical Society of Australia \(psa.org.au\)](#)

<sup>6</sup> [Australian Health Practitioner Regulation Agency - Shared Code of conduct \(ahpra.gov.au\)](#)

<sup>7</sup> [National Consensus Statement: Essential elements for safe and high-quality end-of-life care | Australian Commission on Safety and Quality in Health Care](#)

<sup>8</sup> Access to medicines for palliative care on the PBS<sup>1</sup>, Australian Government Department of Health, Pharmaceutical Benefits Scheme, <http://www.pbs.gov.au/info/publication/factsheets/palliative-care>

<sup>9</sup> End of life directions for aged care. Factsheet: Legal Protection for Administering Pain and Symptom Relief. Available at: <https://www.eldac.com.au/tabid/4985/Default.aspx>

<sup>10</sup> [GP Pharmacological Management.pdf \(palliaged.com.au\)](#)

<sup>11</sup> [QUT - Voluntary Assisted Dying](#)