

End of Life Law in Australia: An Overview for the Aged Care Sector

Health professionals and personal care workers have a significant role in caring for and supporting older people at the end of life. Caring for someone at the end of life can be challenging, especially when it involves interacting with the law. This factsheet gives an overview of end of life law that relates to medical treatment and aged care, and discusses why it is important to know the law.

Clarifying the law

This factsheet explains:

- What end of life law is
- The role of end of life law in aged care
- The Australian legal system
- Key end of life laws relevant to aged care
- Where to go for information about State and Territory end of life laws

What is end of life law?

Broadly, **end of life law covers legal issues that are relevant to medical decisions made at the end of life.**

There are different views across the palliative, aged care, medical and other health sectors about what 'end of life' means. End of life law relates to decisions that happen in the 'last days and months of life', as well as the planning and decision-making that happens well before this, including before a person has an illness or injury.

What is the role of end of life law in aged care practice?

The law establishes a broad framework for end of life decision-making and advance care planning.

Health professionals, including those working in the aged care sector, play important legal roles. For example, in aged care you may be called upon to:

- decide whether to follow a person's Advance Care Directive;
- identify the substitute decision-maker for a person who does not have capacity;
- decide whether life-sustaining treatment can lawfully be withheld or withdrawn;
- determine the appropriate level of pain and symptom relief that can be given to an aged care recipient approaching the end of life; and
- decide whether or not to provide urgent medical treatment, or transfer a person to hospital.

The law also establishes processes for resolving disputes, for example, with families and substitute decision-makers.

Why knowing the law is important

Knowing the law can improve your aged care practice. For example, understanding the law can:

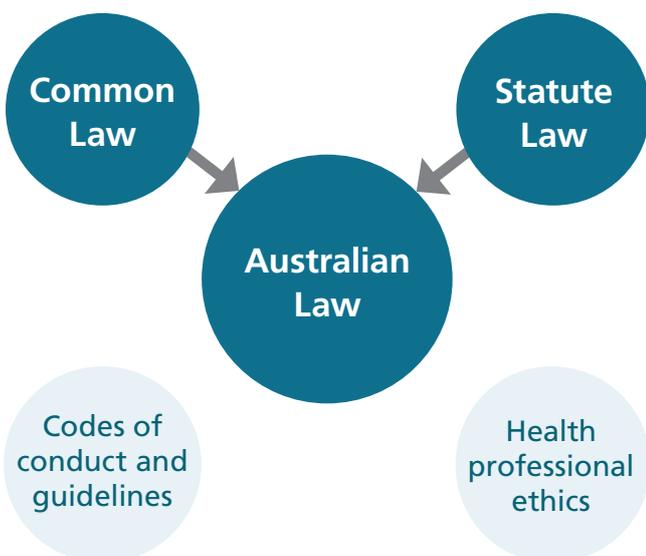
- **Help you to manage difficult situations** that arise in your practice. A common example is uncertainty about whether it is lawful to provide medication for pain and symptom relief to a person. Knowing the law can help you understand what action is allowed, and enable you to provide appropriate care.

- **Improve your communication** with older people, their families and substitute decision-makers. Disputes about treatment and care can often arise because of different understandings about the law.
- **Enhance your confidence and ability to support people receiving aged care**, their families, or your colleagues where legal issues arise. An example is a resident seeking your help to make an Advance Care Directive.
- **Prevent legal risk.** Better legal knowledge can help you to act lawfully, and reduce the risk of criminal or civil liability.

End of life law in Australia

At the end of life, the law that applies can differ depending on whether or not a person has decision-making capacity. The **law also differs across Australia, as each State and Territory has its own law about key areas of end of life** e.g. guardianship and medical treatment legislation.

Law in Australia comes from two main sources: **Common Law** (law made by judges in court decisions) and **Statute Law** (legislation made by Commonwealth, State and Territory parliaments).



Australian health professionals and personal care workers are also regulated by **codes of conduct, quality and safety standards, and guidelines.** **Health professional ethics** also has a role in guiding decision-making.

Codes, guidelines and ethical frameworks are not binding i.e. enforceable in the same way as the law. However, they are important as they establish minimum professional standards of conduct when providing end of life care, and guide ethical decision-making and practice. They are also used by courts, tribunals or disciplinary bodies (e.g. in disciplinary proceedings, cases involving alleged negligence, or other investigations) when they make decisions about appropriate standards of a health professional's or aged care provider's care or conduct.

Applying the law in practice can be complicated

If you are unsure of the law, or how it applies in your aged care practice, you should discuss your concerns with your manager. They may wish to seek legal advice about the appropriate course of action. If you are a GP, you can contact your medical insurer or your medical defence organisation for advice.

Overview: Key areas of end of life law

Capacity and Consent to Medical Treatment

Every adult has the right to decide what is or is not done to their bodies. **For medical treatment to be lawful, a person must consent to it.** If that treatment is given without consent, the health professional who provides it may be liable under civil or criminal law. An exception to this is if the treatment is provided in an emergency in order to save the person's life, and it was not possible to obtain consent from the person or their substitute decision-maker.

Consent to treatment is only valid if the person has 'capacity' or is 'competent' to consent. The **consent must be given freely and voluntarily, and it must relate to the proposed treatment.**

Every adult is presumed to have capacity to make their own medical treatment and health care decisions. **To have capacity the person must be able to:**

- **comprehend and retain the information needed to make the decision**, including the consequences of the decision; and
- **use and weigh that information** as part of their decision-making process.

A person without those abilities will lack capacity for medical decision-making and will not be able to make treatment decisions themselves. In that situation, **there are three ways in which decisions can be made by or for them:**

- Before they lost capacity, the person may have made an **Advance Care Directive** which provides directions about medical treatment.
- A **substitute decision-maker** can make the decision, generally based on what they believe the person would have wanted, and their best interests.
- A **tribunal or the Supreme Court** can provide consent or make a treatment decision.

Advance Care Directives

An Advance Care Directive is an instruction that a person makes now in the event that they might lose capacity in the future to make decisions about their medical treatment or health care. There are **two types of Advance Care Directives:**

- **Common Law Advance Care Directives** governed by the common law (i.e. decisions made by the Courts), and
- **Statutory Advance Care Directives** governed by State and Territory legislation.

Advance Care Directives can be used by a person to communicate specific instructions about types

of treatment, including to request or refuse treatment (e.g. refusing a blood transfusion or cardiopulmonary resuscitation), or their preferences (e.g. not wanting to die in hospital).

Some **Advance Care Directives can also be used to appoint a substitute decision-maker.**

An Advance Care Directive will only apply once the person has lost capacity to make their own decisions, except in the Australian Capital Territory where a Health Direction may also apply when a person has capacity.

Generally, **health professionals must follow a valid and applicable Advance Care Directive** (including a Directive that refuses life-sustaining treatment) and may be liable under civil and criminal law if they do not.

Substitute Decision-Making

A person who has capacity may **appoint someone in their Advance Care Directive or other legal document e.g. an Enduring Power of Attorney to be their substitute decision-maker.** The substitute decision-maker 'stands in the shoes' of the person to make medical treatment decisions when the person no longer has capacity.

Increasingly, it is recognised in law and practice that a person should be supported to make their own decision before substitute decision-making occurs.

Sometimes a person without capacity will not have an Advance Care Directive that makes a decision about the proposed treatment, or have appointed a substitute decision-maker. In those situations, **the guardianship and medical treatment decision-making legislation in each State and Territory sets out an order of who can be the substitute decision-maker** (e.g. a spouse, family member or friend, or a statutory body, such as the Public Guardian or Public Advocate, or a court or tribunal).

Withholding and Withdrawing Life-Sustaining Treatment

It is lawful for a person with capacity to refuse medical treatment. **Health professionals must respect a person's decision to refuse treatment** and, if directed to, they can legally withhold (not start treatment) or withdraw (stop treatment already started) life-sustaining treatment, even if this might result in the person's death.

It can also be lawful for a person's substitute decision-maker to ask that life-sustaining treatment be withheld or withdrawn from the person if they can no longer make treatment decisions themselves.

Legal Protection for Administering Pain and Symptom Relief

Medication is often given to a person with a life-limiting illness who is experiencing pain or symptoms, to maintain or improve their comfort. In some cases, **medication may have the unintended effect of hastening the person's death**. If this occurs, the person who provided the medication (usually a doctor or nurse) **will not be liable for the person's death so long as their intention was to relieve pain or symptoms, and not to hasten death**.

This legal protection forms part of the common law in Australia, and is known as the **doctrine of double effect**. Some Australian States and Territories have incorporated this doctrine into legislation.

Providing medication that ultimately hastens death **is not voluntary assisted dying if the health professional's intention in giving the medication is to reduce pain or symptoms, and not to cause or hasten death**.

It is also **lawful for a person with capacity to refuse food and drink** (either naturally or through artificial measures such as a tube) even if that results in death.

Futile or Non-Beneficial Treatment

Futile or non-beneficial treatment is **treatment which is of no benefit, cannot achieve its purpose, or is not in the person's best interests**.

Health professionals decide whether or not treatment is futile on a case-by-case basis, and **may withhold or withdraw treatment that is futile or non-beneficial**. They have no obligation to provide treatment that is not in the person's best interests, or is inconsistent with good medical practice.

A person or their substitute decision-maker **cannot require or demand that futile or non-beneficial treatment be given**. Their consent is not needed to withhold or withdraw it. A request for futile or non-beneficial treatment in an Advance Care Directive need not be followed.

Queensland's law is different when the person does not have capacity. In that situation, a substitute decision-maker's consent is needed to withhold or withdraw treatment, even if it is futile.

In rare cases, treatment disputes have been considered by courts and tribunals. The primary consideration in those cases is the person's best interests. Courts and tribunals generally agree with clinical assessments of futility.

Urgent (emergency) Medical Treatment

Generally, it is **lawful for a health professional to provide treatment without consent to a person who does not have capacity if there is an urgent need for treatment** e.g. to save a person's life, prevent serious damage to health, or prevent significant pain and distress.

It may still be possible, before urgent treatment is provided, **to obtain consent either from a person with capacity, or their substitute decision-maker if the person does not have capacity**.

In some States and Territories, if a person does not have capacity and needs urgent treatment, the law requires **health professionals to seek consent from the person's substitute decision-maker if it is possible** (e.g. a decision-maker can be located and is available and willing). It is good practice for health professionals in all States and Territories to do this if possible.

Urgent treatment **cannot be provided if it has been lawfully refused:**

- by the person themselves if they have capacity,
- in a valid Advance Care Directive, or
- by a substitute decision-maker.

If an aged care recipient with capacity states they do not want to go to hospital for urgent treatment, or refuses treatment, **their request should be respected**. This is the case even if they require life-sustaining treatment and will die without it. A **health professional who provides treatment contrary to a lawful refusal commits an assault** on the person.

Some States and Territories have forms to guide clinical decision-making about cardiopulmonary resuscitation (CPR) in emergencies e.g. resuscitation plans. Whether or not these should be followed depends on the laws of your State or Territory.

Managing Disputes about Medical Treatment Decision-Making

End of life decision-making can be challenging for everyone involved in a person's care and **sometimes disagreements can occur**. In aged care, these disputes generally arise when there is a disagreement between the care team and a person, their family or substitute decision-maker about a treatment decision.

Most disagreements about medical treatment can be resolved through good communication, shared decision-making, and timely dispute resolution processes within aged care settings.

When a dispute cannot be resolved within aged care, **advice or assistance may be sought from State and Territory guardianship bodies** such as the Public Advocate or Public Guardian, or a lawyer.

State and Territory tribunals are able to hear disputes about end of life medical treatment. Their powers, the orders they may make, and how they make decisions vary depending on the guardianship and medical treatment legislation of the State or Territory.

State and Territory Supreme Courts also have powers to resolve disputes about medical treatment at the end of life. When making a decision for a person without capacity, the courts' paramount consideration is the person's best interests.

Voluntary Assisted Dying

Voluntary assisted dying (VAD) refers to the assistance provided by a health practitioner to a person with a terminal illness, disease or medical condition to end their life. 'Voluntary' means it is the person's voluntary choice. The person must have decision-making capacity to decide to access VAD.

VAD is legal in all Australian States and the Australian Capital Territory. It is available in limited circumstances to people who meet the eligibility criteria.

VAD is illegal in the **Northern Territory**.

Providing appropriate pain and symptom relief with the intention of relieving a person's pain and suffering is not VAD.

Learn more about end of life law

For further information visit:

- the *ELDAC End of Life Law Toolkit* for factsheets, mythbusters and cases studies on each topic above. (<https://www.eldac.com.au/Toolkits/End-of-Life-Law>)
- *End of Life Law in Australia*, a website to assist health professionals and the community to navigate end of life law. It provides information about the law in each Australian State and Territory. (<https://www.end-of-life.qut.edu.au/>)
- *End of Life Law for Clinicians*, a free online training program for medical practitioners, nurses, and allied and other health professionals about end of life law across Australia. (<https://ellc.edu.au>)