

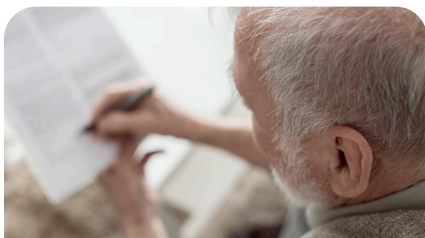
Knowing the law can support you to care for people at the end of life.

Knowing the law can help you to:

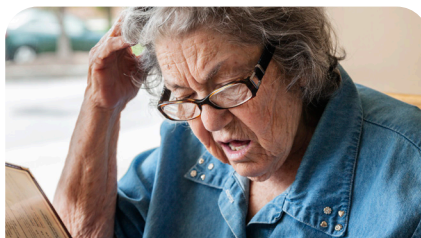
- Support decision-making by the people you care for, families and substitute decision-makers.
- Manage legal issues that arise in aged care with confidence.
- Deliver high-quality, optimal care for older people at the end of life.

End of Life Law Toolkit

Learn about end of life law in aged care in the ELDAC End of Life Law Toolkit, a free resource developed by health professionals and legal experts. The toolkit can support you to know the law across 9 areas:



Advance Care Directives



Capacity and Consent



Emergency Medical Treatment



Futile or Non-Beneficial Treatment



Managing Disputes



Pain and Symptom Relief



Substitute Decision-Making



Voluntary Assisted Dying



Withholding and Withdrawing Treatment

The ELDAC End of Life Law Toolkit contains free printable fact sheets, case studies, and mythbusters. As the law is different in each State and Territory, the toolkit connects you to trustworthy information relevant to your place of work.

Find out more about the toolkit at eldac.com.au

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

Health professionals and aged 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 practice, 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 practice
- The Australian legal system
- Key end of life laws relevant to aged care practice
- 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 lacks 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 emergency 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:

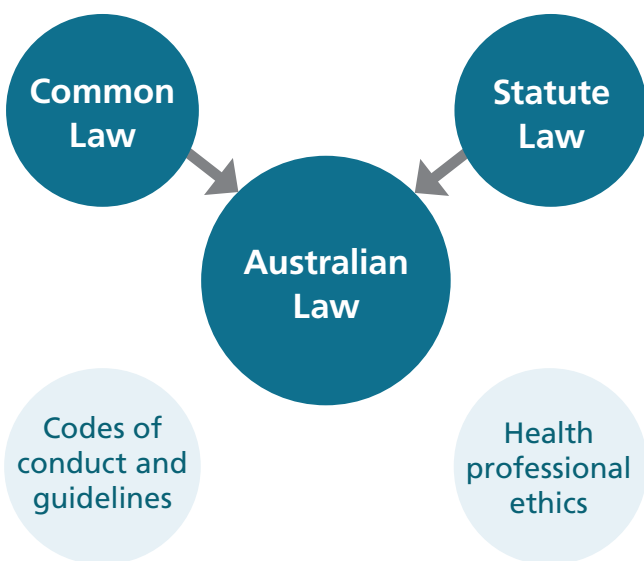
- **Help you to manage difficult situations** that arise in your practice. A common example is uncertainty about whether it is lawful to provide medication for pain and symptom relief to a person. Knowing the law can help you understand what action is allowed, and enable you to provide appropriate care.

- **Improve your communication** with individuals, 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 aged care workers are also regulated by **codes of conduct, 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 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.

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 often used to describe **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 lacks 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.

Emergency Medical Treatment

Generally, it is **lawful for a health professional or aged care worker to provide emergency 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 emergency treatment is provided, **to obtain consent either from a person with capacity, or their substitute decision-maker if the person lacks capacity**.

In some States and Territories, if a person does not have capacity and needs emergency 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.

Emergency 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 emergency 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 an aged care worker or GP and a person, their family or substitute decision-maker about a treatment decision.

Most disagreements about medical treatment can be resolved through good communication 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.

The **State and Territory Supreme Courts** also have powers to resolve disputes about medical treatment at the end of life. When making a decision for adults who lack 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 laws have been passed in all Australian States. In Victoria, Western Australia and Tasmania VAD is operating, and is available in limited circumstances to people who meet the eligibility criteria. VAD laws will **commence operation in Queensland on 1 January 2023, South Australia on 31 January 2023, and New South Wales on 28 November 2023**.

VAD is illegal in the **Northern Territory and the Australian Capital Territory**. Commonwealth laws currently prevent the Territories from legislating on VAD.

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/tabid/4902/Default.aspx>)
- *End of Life Law in Australia*, a website to assist the community to navigate end of life law, and to access 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://palliativecareeducation.com.au/course/index.php?categoryid=5>)

Capacity and consent to medical treatment

A person may consent to or refuse medical treatment if they have decision-making capacity. This factsheet explains the key legal principles on decision-making capacity, and consent to medical treatment.

Clarifying the law

This factsheet explains:

- When consent to treatment is required, and when it will be valid
- When a person will have capacity to make decisions about medical treatment
- Whether a person with capacity can make a decision that others disagree with
- Whether a person's capacity can change over time

Consent to medical treatment when a person has capacity

A person with decision-making capacity has the right to decide what is or is not done to their bodies. This means they **can consent to medical treatment, or refuse it**.

When is a person's consent to treatment required?

Valid consent should be obtained from a person with capacity **prior to examining them or providing medical treatment**.

A health professional who examines or treats a person without consent could be liable under civil or criminal law (for example, being charged with assault), or be subject to disciplinary action.

Consent is not required from a person when:

- **emergency treatment** is needed to save the person's life, prevent serious damage to health, or prevent significant pain and distress; or
- they have **impaired decision-making capacity** (discussed below). In this situation, consent can be provided in an Advance Care Directive or by a substitute decision-maker. This is discussed further in the ELDAC factsheets *Advance Care Directives* (<https://www.eldac.com.au/tabid/4968/Default.aspx>), and *Substitute decision-making* (<https://www.eldac.com.au/tabid/4982/Default.aspx>).

What is valid consent to treatment?

For consent to be valid:

- the person must have **capacity** to consent;
- the person must provide that consent **freely and voluntarily**. This means the decision is made without undue pressure, coercion or manipulation i.e. undue influence; and
- the **consent must apply to the treatment that is given**.

Appropriate advice and decision-making support from the person's family and health professionals will not be undue influence so long as the person is still making the decision they want. However, a person changing their treatment decision when another person is present may alert a health professional to possible undue influence.

Are there formal requirements for consent?

Consent can be given verbally or be implied (for example, if a person offers their arm so that a nurse can take blood). Sometimes, for example, before a major procedure, it may be appropriate to obtain written consent.

A health professional should also provide information about treatment risks and any other information a person needs to provide consent. Not doing this could result in civil liability for not warning about an adverse outcome.

Decision-making capacity

When does a person have capacity?

All adults are presumed to have capacity to consent to or refuse treatment, unless it can be shown that they do not.

A person will have capacity for a medical treatment decision if they can:

- **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.

Information about treatment can include the proposed treatment and alternatives, and the consequences and risks of different treatment options.

Guardianship and medical treatment decision-making legislation in each State and Territory sets out similar capacity tests, but some have additional requirements.

Find out more about decision-making capacity in your State or Territory at *End of Life Law in Australia*. (<https://end-of-life.qut.edu.au/advance-directives/state-and-territory-laws>)

Who decides whether or not someone can make their own decisions?

Generally **capacity is assessed by a person's doctor or a medical practitioner with expertise in capacity assessment**, but in some cases (e.g. if there is doubt about a person's capacity) a court or tribunal might be asked to decide this.

What if a person makes a decision that others disagree with?

A person with capacity **can make a decision that others disagree with**, and that decision must be respected. A person does not lack capacity just because they make a decision someone disagrees with, or that a health professional considers is not in the person's interests.

For example, **a person with capacity can refuse life-sustaining medical treatment, even if it is recommended by a doctor**. (This is discussed further in the ELDAC factsheet *Withholding and withdrawing life-sustaining medical treatment*. (<https://www.eldac.com.au/tabid/4988/Default.aspx>)). Or, they can refuse to be transferred to hospital, even if a health professional or family member thinks they should go.

This is because capacity relates to the person's **ability to make a decision, not what decision they make**. However, an unwise or unusual decision may be a prompt for health professionals to check a person's capacity, for example, by referring the person to a medical practitioner with expertise in capacity assessment.

Can a person have capacity for some decisions but not others?

Some medical treatment decisions are more complex than others. A **person may have capacity to make a simple decision about medical treatment but not a more complex one**.

For serious decisions, such as refusing medication which may be necessary to keep a person alive, the process of understanding, retaining and weighing the information (and risks involved) will be more complex than for more minor decisions, such as consenting to a flu vaccine.

Can a person's capacity change over time?

A person's **capacity to make a decision can also change over time**. For example, a person in aged care may have *fluctuating capacity* because of delirium, some forms of dementia or mental illness.

Capacity will be judged at the time a treatment decision is required. For example, a person may be able to make a decision at one time of day, but not at another time on the same day.

It is important to remember that a person does not lack capacity just because they have a medical condition, mental illness or intellectual disability. They can make their own treatment decisions so long as they meet the test for decision-making capacity.

'Capacity is decision specific so even if you have been diagnosed with dementia, you may still have capacity to make all or at least some of your own decisions, especially if you have been diagnosed with early dementia.'

Decision-making capacity may fluctuate over time and depend on the context such as the time of day, location, noise, stress or anxiety levels, medication, or infection'.

Dementia and your legal rights (<https://www.dementia.org.au/files/NATIONAL/documents/Dementia-and-your-legal-rights.pdf>), Alzheimer's Australia, 2016

Key points to remember

1. A person with capacity must give valid consent before medical treatment can be lawfully provided to them. Treating without consent could lead to civil or criminal liability, except in some limited circumstances.
2. Consent to treatment is valid only when the person has capacity, gives consent freely and voluntarily, and the consent relates to the proposed treatment.
3. An adult is presumed to have capacity to consent to medical treatment, unless it can be proved that they do not.
4. A person will have capacity for a medical treatment decision if they are able to comprehend and retain the information needed to make the decision, and can use and weigh that information when deciding.
5. An adult with capacity can make decisions that others disagree with, including to refuse life-sustaining treatment, or not to be transferred to hospital.
6. A person's capacity should be assessed at the time a treatment decision is needed. A person may have capacity for some decisions but not others, and their capacity to make a decision can change over time.

Myth-busters: Capacity and consent to medical treatment

Myth 1: An adult who makes an unusual decision about medical treatment (for example, refusing to go to hospital even though they are having a heart attack and know they might die) lacks decision-making capacity.

No. An adult is presumed to have capacity to make decisions. An adult with capacity is legally entitled to make decisions that others disagree with. However, a decision that a health professional regards as an unwise or unusual decision may be a prompt for clinicians to check the person's capacity.

Myth 2: A man with pneumonia and early-stage dementia refuses antibiotics and may die if he does not take them. He cannot decide to refuse this treatment because his dementia means he lacks capacity to consent.

No. A diagnosis of dementia does not of itself mean that a person lacks capacity (although it may prompt an assessment of capacity). If the person has capacity despite their dementia, they are able to lawfully refuse life-sustaining treatment at that time (even if it will result in death).

Myth 3: A person must prove that they have decision-making capacity, otherwise they cannot make medical treatment decisions.

No. The law 'presumes' that a person has capacity unless there is reason to believe they do not. If a family member advises that an aged care resident does not have capacity, the residential aged care facility should take steps to be satisfied of this. This could be done, for example, through a capacity assessment conducted by a medical practitioner with expertise in capacity assessment.

A person is able to make their own treatment decisions and provide valid consent so long as they meet the legal test for decision-making capacity discussed in the factsheet.

Capacity and Consent to Medical Treatment Case Study



Nina's story

Nina is 83 years old and has Chronic Kidney Disease (CKD) secondary to Type II Diabetes Mellitus (T2DM). Despite her recent diagnosis of dementia, Nina is still cognitively stable and is able to live independently while receiving regular visits from Susan, a home care nurse, and increased support from her daughter Alison.

Susan has cared for Nina for a significant period of time and as a result, she is familiar with her typically friendly disposition. On one visit however, Nina becomes agitated when Susan attempts to complete her routine blood sugar level test. She reviews Nina's webster pack, and observes that her medications have not been taken for the last 24 hours. When she encourages Nina to take them, Nina appears confused and refuses to take the medications, claiming 'you are trying to kill me'. She tries to stand up but becomes unsteady, and says she feels dizzy. Nina's behaviour is unusual as in Susan's experience Nina is usually cooperative, cognitively alert and orientated.

When Alison arrives, Susan shares her concerns about Nina. Alison agrees that Nina's behaviour is out of character and decides to take Nina to see her GP. When reviewing her recent blood test, Nina's GP realises that her renal function is impaired, and her haemoglobin is 70. He is aware Nina has suffered anaemia several times in recent years. In light of this, her CKD and current symptoms, the GP advises that he wants to admit Nina to hospital for a blood transfusion, and further investigation.

Points for reflection

1. What factors must be satisfied for Nina to have capacity to make medical treatment decisions and to provide valid consent?
2. If you were the GP in this scenario, what would you do to determine if Nina has capacity?
3. In this case, do you think Nina has the capacity to consent to a blood transfusion?
Why or why not?
4. Does Nina's dementia mean that she will always lacks capacity for treatment decisions?

Legal considerations on the points for reflection

1. What factors must be satisfied for Nina to have capacity to make medical treatment decisions and to provide a valid consent?

Nina will have capacity to consent to or refuse medical treatment if she can comprehend and retain the information required to make the decision, including the consequences of that decision. Nina must then be able to use and weigh that information to make a decision.

To provide valid consent, Nina must:

- have decision-making capacity,
- give consent freely and voluntarily without undue pressure or influence, and
- consent specifically to the treatment that will be given – in this case, a blood transfusion.

A clinician must inform Nina about treatment risks and other information relevant to making the decision.

2. If you were the GP in this scenario, what would you do to determine if Nina has capacity?

The GP should explore whether Nina has capacity to consent by asking questions to determine whether she understands that she is anaemic; that she requires a blood transfusion to treat this; and that she understands the associated risks of consenting to or refusing the blood transfusion.

If the GP is uncertain whether Nina has capacity, he should refer Nina for a formal capacity assessment by a medical practitioner with expertise in this.

3. In this case, do you think Nina has the capacity to consent to the administration of a blood transfusion? Why or why not?

It is unlikely that Nina has capacity to consent to the blood transfusion due to her current cognitive state. Her confused behaviour (e.g. claiming that Susan is trying to kill her) indicates that she does not currently have insight into her condition, and that she is unable to make informed decisions about her healthcare at this time. If Nina does not have capacity, provided Alison (her daughter) is Nina's legally recognised substitute decision-maker she may be able to consent to the blood transfusion on Nina's behalf.

Find out more about substitute decision-makers in the **ELDAC Legal Toolkit's *Substitute decision-making resources***. (<https://www.eldac.com.au/tabid/4963/Default.aspx>)

4. Does Nina's dementia mean that she will always lack capacity for treatment decisions?

No. Nina's capacity to consent to treatment must be determined on a case by case basis, at the time treatment is proposed. She will not lack capacity simply because she has dementia. In fact, it is likely in this case that Nina's capacity fluctuates depending on the current state of her health and cognitive condition. Generally her baseline cognition is alert and orientated, and she is usually willing to take her medication. If Nina was not unwell, she may in fact have capacity to make all, or at least some, medical treatment decisions. If there is doubt, a formal capacity assessment should be sought.

Find out more about capacity and consent to treatment in your **State or Territory** at ***End of Life Law in Australia***. (<https://end-of-life.qut.edu.au/capacity>)

Final legal observations

After asking Nina questions about her condition and discussing her symptoms and treatment options, the GP concludes she does not understand her condition or the information about the proposed blood transfusion (including its risks), and that she lacks capacity to consent to it.

If Nina does not have an Advance Care Directive which provides a relevant treatment decision, a substitute decision-maker will be required to consent to a blood transfusion being provided.

Advance Care Directives

An Advance Care Directive can be a useful tool for people to communicate instructions about future health care decisions. This factsheet explains the key legal principles for Advance Care Directives.

Clarifying the law

This factsheet explains:

- What an Advance Care Directive is, and how it can be used
- When a person can make an Advance Care Directive
- What types of Advance Care Directives there are
- When an Advance Care Directive must be followed

About Advance Care Directives

An Advance Care Directive (Directive) is a legal document that a person with decision-making capacity makes about future health care decisions. It can be used to:

1. **Make specific decisions about future treatment.** This can include consenting in advance to treatment but more commonly involves refusing treatment, even if that might result in death.
2. **Express preferences about medical treatment and care** (for example goals of care, or wanting to die at home rather than in hospital) **and personal values** (spiritual, religious or cultural beliefs relevant to the person's care).
3. In most States and Territories, **appoint a substitute decision-maker** to make future health care decisions if the person loses capacity.

Learn more about substitute decision-making in the End of Life Law Toolkit factsheet *Substitute Decision-Making*. (<https://www.eldac.com.au/tabid/4963/Default.aspx>)

Making an Advance Care Directive

An Advance Care Directive will be valid if it is made **voluntarily** by the person (i.e. nobody has pressured the person to make the decision), when the person had capacity. The definition of **capacity** differs between Australian States and Territories. Learn when a person will have capacity in your State or Territory at *End of Life Law in Australia*. (<https://end-of-life.qut.edu.au/capacity>)

A person who has lost capacity cannot make a Directive. In that case, generally a substitute decision-maker e.g. a family member or friend must be called upon to make a decision. Learn more in the End of Life Law Toolkit factsheet *Substitute Decision-Making* factsheet (<https://www.eldac.com.au/tabid/4963/Default.aspx>)

Advance care planning

Advance care planning should be part of routine practice for health professionals providing aged care. For practical tips on how to undertake advance care planning with a person you care for visit *Advance Care Planning Australia* (<https://www.advancecareplanning.org.au/understand-advance-care-planning/advance-care-planning-in-specific-health-settings/advance-care-planning-and-aged-care>) and explore the *Advance Care Planning in Aged Care Implementation Guide*. (<https://www.advancecareplanning.org.au/docs/default-source/acpa-resource-library/acpa-publications/advance-care-planning-in-aged-care-implementation-guide.pdf>)

You can also use *How to do advance care planning: A quick guide for health professionals* (https://end-of-life.qut.edu.au/__data/assets/pdf_file/0016/1040209/How-to-do-Advance-Care-Planning.pdf)

Types of Advance Care Directives

Australia has two types of Advance Care Directives:

- **Common Law Advance Care Directives** which are recognised by the common law (decisions made by judges in the courts) and generally must be followed. These types of Directives exist in **all States and Territories except Queensland**.
- **Statutory Advance Care Directives** which are governed by State and Territory legislation. These types of Directives exist in **all States and Territories except New South Wales**.

Mental health legislation in Victoria and the Australian Capital Territory also allows people with mental health conditions to make specific types of Directives about their treatment preferences. Mental health Advance Care Directives are generally not about end of life decision-making so are not discussed further here.

The law on Advance Care Directives differs across Australia. Learn more about the law in your **State or Territory** at *End of Life Law in Australia*. (<https://end-of-life.qut.edu.au/advance-care-directives/state-and-territory-laws>)

How are Advance Care Directives made?

Common Law Advance Care Directives

A **Common Law Advance Care Directive does not have to be in a particular form – it can be verbal or in writing**. There are no other formal requirements, except that it be made voluntarily, by a person with capacity. Witnesses are not required.

Examples of a Common Law Advance Care Directive include:

- A written document which refuses some type of treatment.
- A card in a person's wallet which refuses treatment (such as a blood transfusion or resuscitation).
- A verbal direction refusing specific treatment that is given to a health professional or aged care worker when the person has capacity.

There is no requirement for the person to first receive information about the treatment they want to refuse or request.

Statutory Advance Care Directives

Most Statutory Advance Care Directives must be:

- **made in writing**. Most legislation about Directives has an 'approved form' which can or must be used. In the Australian Capital Territory and Tasmania, a Statutory Advance Care Directive can also be made orally or in another way,
- **signed by the person making the Directive** (who must have capacity and make the Directive voluntarily), and
- **witnessed**. In some places it must also be witnessed by a health professional.

In some States and Territories, the person must also receive information or medical advice about the treatment they want to refuse or request.

Can a Statutory Advance Care Directive made in one Australian State or Territory apply in another?

Some States and Territories recognise valid Statutory Advance Care Directives that were made interstate (provided certain requirements are met), while others do not.

Even if not formally recognised by another State or Territories' legislation, a Directive could still be a valid Common Law Advance Care Directive which will apply across Australia, except in Queensland where these Directives are not legally binding.

If a person's Directive is not recognised by another State or Territory, it still provides guidance to health professionals and substitute decision-makers about the person's values, choices and treatment preferences.

Learn more about recognition of interstate Advance Care Directives in your **State or Territory** at *End of Life Law in Australia* (<https://end-of-life.qut.edu.au/advance-care-directives/state-and-territory-laws>)

When must an Advance Care Directive be followed?

When Advance Care Directives apply

A Directive will generally apply **only when the person loses capacity** to make the treatment decision. This might occur when the person is unconscious, or has severe cognitive impairment e.g. because of advanced dementia. The Directive must also apply to the health care situation that has arisen.

In the **Australian Capital Territory**, a statutory Health Direction will apply both when the person has capacity or lacks capacity.

Following an Advance Care Directive

Generally, **a valid Directive must be followed** by a health professional, even if it refuses life-sustaining treatment which will result in a person's death. If they do not, a health professional could be liable under the criminal or civil law.

Usually **a person's family or substitute decision-maker cannot disregard specific treatment decisions made by a person in a valid Directive.**

There are some **limited circumstances** in which a Directive does not have to be followed.

Examples are:

- a Directive is too uncertain to guide decision-making,
- circumstances have changed so much since the person made the Directive that it should not be followed, or
- the person has requested futile or non-beneficial treatment.

The law on this differs across Australia.

Learn more about the law on following Common Law Advance Care Directives (<https://end-of-life.qut.edu.au/advance-care-directives/common-law-advance-care-directives>) or Statutory Advance Care Directives (<https://end-of-life.qut.edu.au/advance-care-directives/state-and-territory-laws>) in your **State or Territory** at *End of Life Law in Australia*.

Learn more about futile or non-beneficial treatment in the *End of Life Law Toolkit's Futile or Non-Beneficial Treatment* resources. (<https://www.eldac.com.au/tabid/4962/Default.aspx>)

Practical tips: Advance Care Planning in aged care

It is important to remember that:

- Making an Advance Care Directive is voluntary – a person may choose not to make a Directive, and cannot be required by an aged care provider to do so.
- Only the person can make a Directive. The person's family or substitute decision-maker cannot make a Directive for the person.
- Advance care planning discussions should occur early e.g. when a resident enters aged care. These discussions can also be undertaken by staff with residents (and if the person consents, their family) at any time.
- It is good practice after a person experiences deterioration e.g. is hospitalised and returns to a facility, or experiences a significant change to their health, to revisit advance care planning discussions and/or review existing documents.

For more practical tips and information visit

Advance Care Planning Australia

(<https://www.advancereplanning.org.au/docs/default-source/acpa-resource-library/acpa-publications/advance-care-planning-in-aged-care-implementation-guide.pdf>)

or the End of Life Law Toolkit *Advance Care Directives* resources (<https://www.eldac.com.au/tabid/4961/Default.aspx>)

Key points to remember

1. An Advance Care Directive records a person's decisions, wishes, or values about health care now in case they lack decision-making capacity in the future.
2. It can request or refuse health care, including life-sustaining treatment. In some parts of Australia it can be used to appoint a substitute decision-maker.
3. Advance Care Directives are recognised throughout Australia by the common law (except in Queensland) and by legislation in all States and Territories (except New South Wales). The law is different in each jurisdiction.
4. An Advance Care Directive must be made voluntarily, when the person has capacity. It cannot be made by a person's family or substitute decision-maker.
5. For an Advance Care Directive to apply, the person must not have capacity, and it must relate to the health care situation that has arisen. A Statutory Advance Care Directive must also meet formal requirements of legislation.
6. A health professional generally must follow a valid Advance Care Directive. If they do not, they might be criminally or civilly liable. There are limited situations where a Directive does not need to be followed.

Mythbusters: Advance Care Directives

Myth 1: A person must have an Advance Care Directive

No. Making an Advance Care Directive is every person's choice, and that choice should be respected. Directives are a useful advance care planning tool, but there may be legitimate reasons why a person chooses not to have a Directive.

Myth 2: Advance Care Directives are just recommendations to inform clinical decision-making

No. Advance Care Directives can be legally binding documents that health professionals are obliged to follow. For example, the law will generally require a health professional to follow a refusal of treatment in a Directive where:

- the Directive is legally valid (made voluntarily, when the person had capacity, and meets any formal requirements required by State and Territory legislation), and
- it applies to the health care situation that has arisen.

There are situations where Advance Care Directives do not have to be followed and this varies by State and Territory. Visit **State and Territory Advance Care Directives at End of Life Law in Australia** for more information. (<https://end-of-life.qut.edu.au/advance-care-directives/state-and-territory-laws>)

Myth 3: A person can't use their Advance Care Directive to refuse treatment needed to keep them alive (life-sustaining treatment)

No. A person can refuse life-sustaining treatment in their Advance Care Directive, even if following the Directive will result in death.

Myth 4: A health professional must always give a person the treatment they request in their Advance Care Directive

No. The law generally does not require a health professional to provide treatment they believe is non-beneficial, futile, or not in the person's best interests. Where a person's Advance Care Directive requests such treatment, a health professional does not breach the law, or other professional obligations, by not giving that treatment. The position in Queensland is different where the person does not have capacity, and treatment is futile or non-beneficial.

Learn more in the **End of Life Law Toolkit's Futile or Non-beneficial Treatment factsheet**. (<https://www.eldac.com.au/tabid/4962/Default.aspx>)

Advance Care Directive Case Study



Alistair's story

Alistair has Coronary Heart Disease (CHD) and Parkinson's disease. After experiencing a Cerebral Vascular Accident last year, Alistair's cognition and functional ability has significantly deteriorated. Upon routine review, Alistair's GP Elizabeth believes his Parkinson's disease is entering its later stages.

Until now Alistair and his wife Mary have lived independently while receiving occasional help from their daughter, Helen. Due to worsening arthritis, Mary can no longer care for him, and they reluctantly decide that Alistair should move into Hilltop Grove, a residential aged care home.

By the time Alistair transitions to Hilltop Grove his Parkinson's disease has deteriorated significantly and he no longer has capacity to make medical treatment decisions. Mary provides the Nurse Manager with Alistair's Advance Care Directive. It was made when Alistair had capacity, and refuses life-sustaining treatment, as well as antibiotics.

Two months later, Alistair contracts severe Community Acquired Pneumonia and Elizabeth attends Hilltop Grove to review his condition. She observes that his vital signs are unstable and that he is deteriorating due to the severity of the infection. Hilltop Grove's Manager contacts Mary and Helen to advise them of Alistair's condition.

Elizabeth reviews Alistair's Advance Care Directive and, in accordance with his refusal of life-sustaining treatment, does not call an ambulance or administer antibiotics. She instructs the Hilltop Grove nursing staff to focus Alistair's care on ensuring his comfort, and charts medications to adequately manage his symptoms.

Helen arrives at Hilltop Grove alone as Mary is unwell. She becomes distressed when she speaks to a nurse attending to Alistair and learns that no treatment other than medication for pain and symptom relief has been provided. She is unaware of Alistair's Directive and believes that Elizabeth should be providing medical interventions to save his life.

Points for reflection

1. Was Elizabeth's decision not to provide antibiotics lawful?
2. Are there any circumstances in which Elizabeth would be justified in not following Alistair's Advance Care Directive?
3. If you were Elizabeth, how would you approach your discussion with Helen about Alistair's care? Is there anything Elizabeth could have done differently?

1. Was Elizabeth's decision not to provide antibiotics lawful?

Generally, a valid Advance Care Directive must be followed by a health professional, even if it refuses life-sustaining treatment that is needed for the person to live.

In States and Territories which have **Statutory Advance Care Directives** governed by legislation (all jurisdictions except New South Wales), Alistair's Advance Care Directive will be valid if it is:

- **in writing** (usually using an approved form outlined in State and Territory legislation). In the Australian Capital Territory and Tasmania, it can also be made verbally or in another way,
- **signed by Alistair** (who must have made the Directive voluntarily when he had decision-making capacity),
- **witnessed**, and
- **applicable to the medical situation.**

The Directive must also comply with any other legislative requirements e.g. receiving information or medical advice before completing it.

In States and Territories which have **common law Advance Care Directives (all States and Territories except Queensland)**, Alistair's Directive will be valid, regardless of whether it is verbal or in writing, so long as it was **made voluntarily, when Alistair had capacity.**

In **Queensland**, an Advance Health Directive which refuses life-sustaining treatment will only apply if certain conditions are met.

Learn more about Queensland's law on Advance Health Directives at *End of Life Law in Australia*. (<https://end-of-life.qut.edu.au/advance-directives/state-and-territory-laws/queensland#547671>)

Here, there is no reason to suggest that Alistair's Directive is not valid. It applies to Alistair's medical situation as it refuses life-sustaining treatment and antibiotics. Elizabeth acted lawfully by following Alistair's Directive and treatment refusal. If Elizabeth had provided Alistair antibiotics, she may be liable under criminal or civil law for committing an assault.

2. Are there any circumstances in which Elizabeth would be justified in not following Alistair's Advance Care Directive?

There are **limited circumstances where an Advance Care Directive does not need to be followed**. These differ in each State and Territory. Some common examples are:

- Where a Directive is too uncertain or ambiguous to guide medical decision-making.
- Where the person's circumstances have changed to such an extent since the Directive was made that it should not be followed.
- Where a Directive requests treatment that the health professional believes is non-beneficial, futile or not in the person's best interests.

In **Queensland**, a health professional does not have to follow a direction in an Advance Health Directive that is uncertain or inconsistent with good medical practice.

As none of these circumstances exist in Alistair's situation, there is no reason why Elizabeth should not follow Alistair's Advance Care Directive.

The law on following Advance Care Directives varies across Australia. Learn about the law in each **State and Territory** at *End of Life Law in Australia*. (<https://end-of-life.qut.edu.au/advance-directives/state-and-territory-laws>)

3. If you were Elizabeth, how would you approach your discussion with Helen about Alistair's care? Is there anything Elizabeth could have done differently?

Elizabeth should communicate openly with Helen about Alistair's Advance Care Directive and treatment preferences. This could involve discussing:

- The purpose of an Advance Care Directive e.g. to record a person's decisions, preferences or values around their medical treatment and care where they lack decision-making capacity, and that it enables Alistair's treatment choices to be respected.
- That a person can refuse life-sustaining treatment in their Advance Care Directive even if following that request will result in their death.
- That a Directive is a legally binding document that health professionals are obliged to follow.

It would also be helpful for Elizabeth to listen to Helen's concerns and answer any questions about Alistair's condition and future management.

Better practice in this scenario may have been for Elizabeth or her colleagues to have met with Helen immediately on her arrival to discuss Alistair's prognosis and the implications of his Advance Care Directive. This approach may have enabled early, proactive management of the situation and reduced Helen's distress.

For further tips on managing end of life conversations with the people you care for and/or their families, refer to:

- the End of Life Law Toolkit's: *Managing Disputes about Medical Treatment Decision-Making* resources (<https://www.eldac.com.au/tabid/5281/Default.aspx>)
- *End of Life Essentials education modules* (<https://www.endoflifeessentials.com.au/tabid/5195/Default.aspx>)
- *CareSearch Patients' and Families' Experience of End-of-Life Care* (<https://www.caresearch.com.au/caresearch/tabid/740/Default.aspx>)

Final legal observations

Alistair had a valid Advance Care Directive that was made voluntarily when he had the capacity to do so. It refused life-sustaining treatment and antibiotics, and was relevant to the medical situation. Elizabeth therefore acted lawfully in following the Directive and complying with Alistair's refusal of treatment.

Substitute decision-making

As a person ages, they sometimes lose their ability to make decisions about health care. When this happens, health care decisions will need to be made by someone else. That person is commonly referred to as a substitute decision-maker. This factsheet explains the key legal principles on substitute decision-making.

Clarifying the law

This factsheet explains:

- The role of a substitute decision-maker
- How a substitute decision-maker is appointed
- Who can be a substitute decision-maker
- What decisions a substitute decision-maker can make
- How substitute decision-makers make decisions
- When a substitute decision-maker's decision must be followed

What is the role of a substitute decision-maker?

A substitute decision-maker is a person who makes a health care decision for a person who has lost capacity.

The substitute decision-maker stands in the shoes of the person to make the decision about health care. Generally the substitute decision-maker's decision has the same legal effect as if the person had capacity and made the decision themselves.

A substitute decision-maker will not need to make the decision if the person without capacity has an Advance Care Directive that applies to the situation.

Who will be the substitute decision-maker?

A person who has capacity can plan for a later time when they may lose capacity by appointing someone to be their substitute decision-maker. This is done by completing a formal document. The document used is different in all States and Territories.

Find out which document is used to appoint a substitute decision-maker in your **State or Territory** at *End of Life Law in Australia*. (<https://end-of-life.qut.edu.au/stopping-treatment>)

If a person has not appointed someone to make decisions for them, then the laws in all States and Territories set out who will be the substitute decision-maker. This person is usually someone who has a close and continuing relationship with the person such as a spouse or other family member. A person who is listed in records as the 'next of kin' will not necessarily be the substitute decision-maker.

Where there is more than one potential decision-maker, the law sets out an order to determine who will be recognised as the substitute decision-maker.

If the person does not have someone close to them to make these kind of decisions, then a public official may be able to make the decision on their behalf. Sometimes, a Tribunal will appoint a guardian to make the health decision.

Who may be a substitute decision-maker and the terminology given to them differs throughout Australia. Find out more about who may be a substitute decision-maker in your **State or Territory at *End of Life Law in Australia***. (<https://end-of-life.qut.edu.au/stopping-treatment>)

What decisions can a substitute decision-maker make?

A substitute decision-maker can make most health care decisions for a person who has lost capacity. These decisions can also include health care decisions about whether life-sustaining treatment should be provided or withdrawn.

Whether or not a substitute decision-maker has power to make a health decision will depend on the particular law of the State or Territory.

Find out more about substitute decision-makers' powers in your **State or Territory at *End of Life Law in Australia***. (<https://end-of-life.qut.edu.au/stopping-treatment>)

What should a substitute decision-maker consider when make a decision?

The laws in each State and Territory differ on this. But generally a substitute decision-maker needs to consider the following things when making a decision about health care:

- what would the person have wanted if they had capacity; and
- what would be in the person's best interests after considering such things as potential risks, burdens and benefits of treatment?

Find out more about the substitute decision-maker's powers in your **State or Territory at *End of Life Law in Australia***. (<https://end-of-life.qut.edu.au/stopping-treatment>)

In some cultures end-of-life decision-making is a collective process, involving the individual, their family and community. Be mindful that some people may wish to include their extended family and community members in decisions about health care and future planning discussions. Sometimes interpreters may be required. Learn more at Caresearch. (<https://www.caresearch.com.au/Caresearch/tabid/109/Default.aspx>)

Should a substitute decision-maker's decision be followed?

Generally, a substitute decision-maker's decision should be followed. This is so even if the decision is to refuse life-sustaining treatment which could result in the person's death.

A health professional might be liable under criminal or civil law or subject to disciplinary action if they provide treatment that has been refused by a substitute decision-maker.

The situation is complex if the substitute decision-maker is requesting treatment that a health professional considers to be futile or not in the person's best interests. This situation is discussed further in the Legal Toolkit factsheet 'Futile and non-beneficial treatment'.

Find out more about the need to follow a substitute decision-maker's decision in your **State or Territory at *End of Life Law in Australia***. (<https://end-of-life.qut.edu.au/stopping-treatment>)

Key points to remember

1. A substitute decision-maker can make a health care decision for a person who does not have capacity, and has not set out their treatment decision in an Advance Care Directive.
2. If a person has not appointed a substitute decision-maker, a Tribunal can appoint a decision-maker for them. But often, the substitute decision-maker will be a spouse or other family member. If there is no one who can act in this role, a public official might make the decision.
3. The law in all States and Territories sets out who will be the substitute decision-maker in a particular situation. The legislation and terminology for a substitute decision-maker is different in each jurisdiction.
4. Substitute decision-makers can make most decisions about health care, even decisions about treatment at the end of life. However, the law can be complex and differs between States and Territories.
5. When making decisions about health care, substitute decision-makers must generally think about what decision the person would have made and what would be in the person's best interests.
6. A decision made by a substitute decision-maker about health care must generally be followed by a health professional.

Myth-busters: Substitute decision-making

Myth 1: If a person doesn't have decision-making capacity, decisions about health care should be made by his or her 'next of kin'

No. *'Next of kin' is an informal term commonly used to refer to a person's immediate or close family members. The term is not recognised in the laws about decision-making for health care.*

The person who will make a health care decision for a person who lacks decision-making capacity will be the person's 'substitute decision-maker'. Who will be the substitute decision-maker for the person will depend on the legislation in your State or Territory.

Myth 2: My patient has lost capacity and has several close family members who visit regularly. I can ask any of them to make a treatment decision for my patient if a decision is needed while they are visiting

No. *The guardianship and medical treatment legislation in each State and Territory sets out an 'order of priority' of people who can be a person's substitute decision-maker. The first person in that order who is willing, available and able to make the decision is the substitute decision-maker.*

Substitute Decision-Making Case Study



Vivian's story

Vivian is an 80-year-old resident of the Sapphire Peaks Residential Aged Care home. She is generally well. While boarding the shuttle bus to do her weekly shopping, Vivian missed her footing and fell backwards, hitting her head on the pavement. She rapidly became unresponsive and was rushed to the closest Emergency Department.

Vivian is unconscious and does not have capacity to make decisions about medical treatment. The medical team discuss Vivian's treatment options with her family and friends who have arrived at the hospital. Among those present are her children Amy (aged 47) and James (aged 45), their father Ed (Vivian's ex-husband who she divorced 15 years ago, and who is visiting with Amy from interstate), and Vivian's sister Rachel, who has a close relationship with Vivian. Amy and James are also close to their mother and visit her often.

The Neuro-Surgical specialist team advise that due to her severe head injury, Vivian requires urgent surgery to relieve intercranial pressure caused by the bleeding around her brain. The surgery is needed for Vivian to survive, but it is an invasive procedure, and given her age and the extent of the trauma there is a risk that she may not survive the anaesthesia or operation.

Vivian does not have an Advance Care Directive, or a guardian or attorney, so a substitute decision-maker's consent is needed to proceed with the surgery. Amy recalls a recent conversation with her mother, following a friend's death, where she told Amy that she would not want to have any major operations or medical treatment at this stage of her life, and would not want to be kept alive if she were dying. Ed remembers Vivian having similar conversations with him when they were married. Amy and James want to respect their mother's wishes and although devastated, they decide not to consent to the operation. Rachel is horrified and cannot bear the thought of Vivian dying if there is a chance she might survive. She begs Amy and James to reconsider.

Points for reflection

1. Who is Vivian's legally recognised substitute decision-maker?
2. What happens if there is a disagreement among decision-makers about Vivian's treatment?
3. Can Vivian's substitute decision-maker/s refuse consent to the operation?
4. What factors should Vivian's substitute decision-maker/s consider when making the decision?
5. Does the clinical team have to follow the decision?

Legal considerations on the points for reflection

1. Who is Vivian's legally recognised substitute decision-maker?

As Vivian does not have an Advance Care Directive, or appointed guardian or attorney, the laws in all States and Territories set out a hierarchy of 'default' substitute decision-makers (known as a person responsible, Statutory Health Attorney, medical treatment decision-maker or health attorney, depending on the State or Territory). The appropriate decision-maker is usually someone who has a close and continuing relationship with the person e.g. the person's spouse or another family member.

As Vivian is divorced from Ed, he is no longer her spouse and cannot be her decision-maker. Applying the law in each State and Territory, Vivian's decision-makers are as follows:

- In **Queensland, South Australia, Tasmania, the Australian Capital Territory and New South Wales** Vivian's relatives who have a close and continuing relationship with her can make the decision. Therefore, **Amy, James and Rachel** can be her decision-makers. In the **Australian Capital Territory**, the health professional may ask the decision-maker they believe is best able to represent the person's views to give consent. For more information on the law in the **Australian Capital Territory** visit *End of Life Law in Australia*. (<https://end-of-life.qut.edu.au/stopping-treatment/adults/state-and-territory-laws/australian-capital-territory>)
- In **Victoria**, Vivian's adult children who have a close and continuing relationship with her (Amy and James) are higher on the list of decision-makers than an adult sibling (Rachel). Where there are two or more adult children, the eldest can make the decision, in this case, **Amy**.
- In **Western Australia**, Vivian's nearest relative who maintains a close relationship with her is her decision-maker. In the order of priority among relatives, a person's children (Amy and James) are higher in the list than a sibling (Rachel). Therefore, **Amy and James** can be Vivian's decision-makers.
- In the **Northern Territory** default decision-makers do not exist. Consent would need to be provided by the **Northern Territory Civil and Administrative Tribunal**.

2. What happens if there is a disagreement among decision-makers about Vivian's treatment?

When disputes arise, it is rare for the guardianship and other legal systems to become involved, and for cases to be decided by courts or tribunals. Most conflicts are managed within the treating hospital or health service using internal dispute resolution policies or procedures. These seek to facilitate open communication and achieve consensus among decision-makers through processes such as clinical reviews, obtaining an independent second medical opinion, family or case conferences, and mediation. Legal advice may also be sought from the healthcare services' legal team.

In some States and Territories, guardianship and medical treatment legislation sets out how disagreements can be resolved. This may involve referring the disagreement for dispute resolution (e.g. through the Public Guardian in some jurisdictions), and, as a last resort, applying to tribunals or courts to make the decision.

This area of law is different in each **State and Territory**. For further information visit *End of Life Law in Australia*. (<https://end-of-life.qut.edu.au/stopping-treatment/adults/state-and-territory-laws>)

In this case, Rachel disagrees with Amy and James and wants Vivian to have the operation. In practice the hospital would most likely hold a family meeting to attempt to reach consensus among them.

Find out more on how to manage disputes about medical treatment decision-making in the **ELDAC Legal Toolkit's *Managing disputes about medical treatment decision-making resources***. (<https://www.eldac.com.au/tabid/5281/Default.aspx>)

3. Can Vivian's substitute decision-maker/s refuse consent to the operation?

A substitute decision-maker can make most medical treatment decisions for a person who has lost capacity, including decisions about whether life-sustaining treatment should be provided, withheld or withdrawn.

The law on what decisions can be made varies by State and Territory. In all **States and Territories except the Northern Territory**, Vivian's decision-maker/s is able to refuse consent to the operation. In the **Northern Territory**, the Northern Territory Civil and Administrative Tribunal has power to refuse consent.

This area of law can be complex, especially in relation to stopping life-sustaining treatment once it has started.

Find out more about what decisions a substitute decision-maker can make in your State or Territory at *End of Life Law in Australia*. (<https://end-of-life.qut.edu.au/stopping-treatment/adults/state-and-territory-laws>)

4. What factors should Vivian's substitute decision-maker/s consider when making the decision?

In making the treatment decision, Vivian's substitute decision-maker/s should consider:

- what Vivian would have wanted, if she had capacity; and
- whether treatment would be in Vivian's best interests, after considering the potential risks, burdens and benefits of the treatment.

The laws in each State and Territory also set out principles to guide substitute decision-makers e.g. decision-making principles, health care principles.

The principles in most jurisdictions require substitute decision-makers to consider the person's:

- interests and welfare
- views, preferences and wishes (if known); and
- treatment options, risks and alternatives.

Here Vivian's decision-maker/s should take into consideration Vivian's previous statements about her treatment preferences e.g. that she does not want any major operations or medical treatment, and does not want to be kept alive if she is dying. The risks of the surgery (e.g. death); other available treatment options (here, there are none); the benefits of future treatment (she may survive) and the burdens (including what her prognosis would be if she does survive); and other decision-making principles in her jurisdiction should also be considered.

Find out more about making substitute decisions in your State or Territory at *End of Life Law in Australia*. (<https://end-of-life.qut.edu.au/stopping-treatment/adults/state-and-territory-laws>)

5. Does the clinical team have to follow the decision?

Generally a substitute decision-maker's decision should be followed, even if refusing treatment will result in a person's death. If the clinical team undertakes the surgery without first obtaining consent from a substitute decision-maker, they could be liable under criminal or civil law or be subject to disciplinary action.

If a clinical team is concerned about the decision a substitute decision-maker makes, advice may be sought from the hospital or health service's legal team, or a medical defence insurer. In some State and Territories, the Public Guardian or Public Advocate's office may be able to provide information or assistance.

Final legal observations

Vivian's legally recognised substitute decision-makers (which vary depending on which State and Territory Vivian is in) must decide whether or not to consent to the operation. In doing so they must take into consideration the factors discussed in reflection point 4. If there is disagreement among Vivian's decision-maker/s, a meeting could be held with the clinical team to reach consensus. In this scenario the clinical team should follow the substitute decision-maker's/s' decision about Vivian's treatment, unless they have concerns about the decision, in which case legal advice should be sought.

Withholding and withdrawing life-sustaining medical treatment

Decisions to withhold or withdraw life-sustaining medical treatment can be difficult. Sometimes they are made by the person themselves (if they have capacity), and sometimes they are made on behalf of the person (if they no longer have capacity). This factsheet explains the key legal principles about withholding and withdrawing life-sustaining treatment.

Clarifying the law

This factsheet explains:

- What is 'life-sustaining treatment'
- When a decision to withhold or withdraw life-sustaining can be made
- Who can make the decision
- When the decision must be followed

What is life-sustaining treatment?

'Life-sustaining treatment' is treatment that is needed to prolong a person's life. Examples include cardiopulmonary resuscitation, artificial hydration and nutrition, artificial ventilation, and in some circumstances, antibiotics and blood transfusions.

When is it lawful to withhold or withdraw treatment?

A decision to withhold or withdraw treatment is a common feature of medical practice when a person is approaching the end of life. The law that governs this practice will differ depending on whether the person has capacity to make treatment decisions.

Where the person has capacity

A person with capacity may refuse any medical treatment, even if it is needed to keep the person alive. **It is lawful for a health professional to withhold or withdraw treatment from a person with capacity who has refused that treatment.** In fact, a health professional who provides treatment contrary to a refusal will have committed an assault on the person.

Where the person does not have capacity

The law is more complex when a person does not have capacity to make a treatment decision. However, a decision to withhold or withdraw life-sustaining treatment can still be lawful in some cases. These include:

1. When the person has an **Advance Care Directive which refuses that treatment.**
2. **When providing the treatment would not be in the person's best interests.** This is sometimes referred to as treatment that is 'futile' or non-beneficial.

An example of this kind of treatment may be the artificial nutrition or hydration of a person in the final stages of Alzheimer's disease who can no longer swallow.
3. A **decision made by the person's substitute decision-maker** to withhold or withdraw treatment. The law on this is not the same throughout Australia. It is important to **consult the guardianship and medical treatment legislation in your State and Territory** (<https://end-of-life.qut.edu.au/stopping-treatment>) to determine when a substitute decision-maker can make this kind of decision.

Find out more about the law on withholding and withdrawing treatment in your State or Territory at *End of Life Law in Australia*. (<https://end-of-life.qut.edu.au/stopping-treatment>)

Decision-making about life-sustaining treatment is discussed further in the Legal Toolkit factsheets 'Advance Care Directives' and 'Substitute decision-making'.

In some cultures end-of-life decision-making is a collective process, involving the individual, their family and community. Be mindful that some people may wish to include their extended family and community members in treatment decision-making and future planning discussions. Sometimes interpreters may be required. Learn more at *Caresearch*. (<https://www.caresearch.com.au/Caresearch/tabid/109/Default.aspx>)

Does a decision to withhold or withdraw treatment have to be followed?

Generally a **health professional must follow a decision to withhold or withdraw treatment** made:

- by a **person who has capacity**,
- **in a valid Advance Care Directive** (made when the person had capacity), or
- by a **person's substitute decision-maker**.

If they do not, a health professional could be liable under the criminal or civil law, and subject to disciplinary sanction.

However, generally a **health professional does not have to provide treatment that they consider is of no benefit, not in the person's best interests, or futile**, even when it is demanded by a person or their substitute decision-maker.

The position is different in Queensland when the person does not have capacity and their substitute decision-maker is wanting treatment. For more information on the Queensland law, please refer to *End of Life Law in Australia* (<https://end-of-life.qut.edu.au/stopping-treatment/adults/state-and-territory-laws/queensland>). These issues are also discussed further in the Legal Toolkit factsheet 'Futile or non-beneficial treatment'.

Disputes about withholding or withdrawing treatment

These kinds of decisions can be very challenging. Sometimes disputes arise between the person, health professionals, families and substitute decision-makers about whether treatment should be withheld or withdrawn.

Find out more about how to resolve disputes in this kind of situation in your State or Territory at *End of Life Law in Australia*. (<https://end-of-life.qut.edu.au/stopping-treatment>)

Key points to remember

1. A decision to withhold or withdraw life-sustaining treatment is a common feature of medical practice when caring for people who are approaching the end of life.
2. A person who has capacity can lawfully refuse treatment even if that treatment is needed to keep them alive. Such a refusal should be followed. The same is generally the case if the person's refusal is contained in an Advance Care Directive that was completed when they had capacity.
3. If the person does not have capacity, their substitute decision-maker can, in some cases, decide to withhold or withdraw treatment. The law on this is more complex and will depend on the guardianship and medical treatment legislation in each State and Territory.
4. A health professional may be liable under the criminal or civil law if they do not comply with a request to withhold or withdraw treatment.
5. A health professional generally has no duty to provide futile treatment, even if it is demanded by a person, their family or substitute decision-makers.

Myth-busters: Withholding and withdrawing life-sustaining treatment

Myth 1: A person or their substitute decision-maker cannot refuse treatment needed to keep the person alive

No. *The law allows all adults with capacity to decide what is, or is not done to their bodies. They can consent to or refuse medical treatment. Therefore, a person can refuse medical treatment even if that treatment is needed to keep them alive.*

Myth 2: A health professional who withholds or withdraws life-sustaining treatment performs euthanasia or physician-assisted suicide

No. *No. A health professional does not perform euthanasia or physician-assisted suicide by withholding or withdrawing treatment even if that treatment is needed to keep the person alive.*

Euthanasia or physician-assisted suicide occurs when the health professional intends to bring about a person's death by actively administering a drug to the person, or providing the drug for the person to take.

Withholding and withdrawing life-sustaining treatment is an accepted and common part of medical practice. It will be lawful provided any necessary consents are obtained. When life-sustaining treatment is withheld or withdrawn, the person is considered to have died naturally from their medical condition or disease.

Withholding and Withdrawing Life-Sustaining Medical Treatment Case Study



Renata's story

Renata is an 82-year-old resident at the Calypso Aged Care Home. Two years ago, she was diagnosed with advanced bowel cancer and received 3 intensive cycles of chemotherapy treatment after undergoing a bowel resection to create a permanent colostomy. Renata was aware that her cancer was incurable but with the help of her husband, she remained well and enjoyed a reasonable quality of life.

At the end of last year Renata's husband passed away suddenly. Following his death she became socially isolated and found it increasingly difficult to care for herself. With her children's support she moved into Calypso.

Not long after settling into Calypso, Renata began experiencing right-sided chest and upper abdominal pain. Following further investigations, Renata's oncologist, Rajesh, advises that the cancer has metastasised to her right lung, liver, and bones. He advises Renata to consider palliative chemotherapy as it may manage her disease symptoms and possibly prolong her life. Renata's son, Alejandro, is at the consultation and tells Rajesh he wants his mother 'to do everything possible and keep fighting it'. Renata reluctantly agrees to schedule chemotherapy for later that week.

After the appointment, Renata returns to Calypso and reflects on her diagnosis. She is fatigued, and feels that her strength is deteriorating due to her age and conditions. She previously experienced severe side effects from chemotherapy and understands the palliative treatment will only temporarily extend her life but not cure her condition.

Later that week, Alejandro takes Renata to her appointment where she advises Rajesh that after much careful thought she does not want chemotherapy, and would prefer to focus on spending the time she has left with her family. Alejandro becomes extremely distressed and demands that Rajesh 'make my mother have the chemo!'.

Points for reflection

1. Is it lawful for Renata to refuse chemotherapy, even if she will die sooner without that treatment?
2. Does Rajesh have to follow Renata's decision?
3. Can Alejandro demand that Renata have the treatment?
4. What if Renata did not have capacity to make a decision about chemotherapy?

Legal considerations on the points for reflection

1. Is it lawful for Renata to refuse chemotherapy, even if she will die sooner without that treatment?

The law presumes that all adults have capacity to consent to or refuse treatment, unless it is shown otherwise.

A person with capacity may refuse medical treatment, even if it is treatment needed to keep them alive. This is because **capacity relates to a person's ability to make a decision, not what decision they make**. However, unwise or unusual decisions may be a prompt to check a person's capacity.

Renata will have capacity if she:

- is able to comprehend and retain the information needed to make the decision, including the consequences of the decision; and
- can use and weigh that information when deciding.

If Renata has capacity, provided her consent has been given freely and voluntarily (and relates to the proposed treatment) she can lawfully refuse the chemotherapy.

Renata appears to understand the proposed treatment, and the consequences of having, or refusing the chemotherapy (she knows that if she does not have it the cancer will spread and cause death). She has considered the information provided by Rajesh and has weighed it. For example, she has considered that the chemotherapy may prolong her life, but also its other implications including the potential for side effects and diminished quality of life. She has used and balanced that information against the consequences of refusing treatment, as part of her decision-making process.

Find out how to determine if a person has capacity to consent to medical treatment in the **ELDAC Legal Toolkit's *Capacity and consent to medical treatment resources*** (<https://www.eldac.com.au/tabid/5268/Default.aspx>)

2. Does Rajesh have to follow Renata's decision?

A health professional must follow a decision to withhold or withdraw treatment made by a person who has capacity. In fact, a health professional who provides treatment contrary to a refusal will have committed an assault on the person, and may be subject to civil, criminal or disciplinary action. Therefore, if Renata has capacity Rajesh should accept her decision not to have chemotherapy.

3. Can Alejandro demand that Renata have the treatment?

No. If Renata has capacity, her decision to refuse treatment must be followed, even if Alejandro or others disagree with her decision.

4. What if Renata did not have capacity to make a decision about chemotherapy?

Where a person does not have capacity, a decision to withhold or withdraw life-sustaining can still be made:

- in a valid Advance Care Directive (made when the person had capacity); or
- by a person's substitute decision-maker, provided they have the power to do this under the law of their State or Territory.

Find out more about substitute decision-makers' powers in your **State or Territory** at ***End of Life Law in Australia*** (<https://end-of-life.qut.edu.au/stopping-treatment/adults/state-and-territory-laws>)

In making a decision to withhold or withdraw treatment from a person without capacity, a substitute decision-maker generally needs to consider:

- what the person would have wanted if they had capacity; and
- what would be in the person's best interests after considering such things as potential risks, burdens and benefits of treatment.

Renata does not have an Advance Care Directive refusing treatment, so her substitute decision-maker would need to consider whether or not to consent to the chemotherapy. If Alejandro is her lawfully recognised substitute decision-maker, he would need to consider Renata's best interests and preferences in order to reach a decision.

For more information about substitute decision-making visit the **ELDAC Legal Toolkit *Substitute decision-making resources*** (<https://www.eldac.com.au/tabid/4963/Default.aspx>)

Final legal observations

After further discussion, Rajesh considers Renata understands the proposed treatment, and the consequences of undergoing the treatment as well as refusing the treatment (e.g. that she will die). He believes she has considered the information provided and weighed it to arrive at her decision e.g. she has considered that the chemotherapy may prevent the cancer, but may also cause side effects; that it may prolong her life only temporarily; and her preference to spend time with her family. The law recognises Renata's ability to choose not to have chemotherapy, which Rajesh must respect.

Medication for pain and symptom relief for people with a life-limiting illness

Medication for pain and symptom relief (palliative medication) is important to ease suffering and improve the quality of life of a patient with a life-limiting illness. However, uncertainty can arise for those giving palliative medication about whether it is lawful, particularly where a patient is close to death. This factsheet explains key legal principles about providing palliative medication.

Clarifying the law

This factsheet explains:

- Why appropriate palliative medication is lawful
- What legal protection is available where a patient dies following palliative medication
- That giving appropriate palliative medication is not euthanasia
- That palliative medication can be given to relieve suffering caused by a patient refusing food and water

About palliative medication

Palliative medication is a key part of good palliative care. It helps manage the pain and symptoms of a person with a life-limiting illness. Palliative medication can be given in hospital, residential aged care or at home. Medication used includes morphine and sedatives.

There are varying clinical views about whether or not some palliative medication may hasten death. However, the law recognises that **palliative medication used for pain and symptom relief is lawful in Australia** so long as the intention of the person giving the medication is to relieve the patient's pain and suffering and not to cause death.

Legal protection when a patient dies

In some cases it is possible for palliative medication to have the 'double effect' of relieving pain and suffering as well as hastening a person's death.

In those situations the **doctrine of double effect** ('double effect') can provide legal protection to the person who gave the medication so they are not criminally liable for the death.

What is double effect?

Double effect recognises that giving medication to a patient is lawful, even if it may hasten death, so long as the intention is to relieve pain and not hasten death.

Double effect is part of Australian law.

In **Queensland, Western Australia, South Australia** and the **Australian Capital Territory** there is also legislation which recognises double effect.

Find out more about the law in your State or Territory at *End of Life Law in Australia*. (<https://end-of-life.qut.edu.au/palliative-care>)

In what setting will double effect apply?

Double effect can apply when the person's death occurs in a hospital, residential aged care facility or other health service. It can also apply when the person dies at home.

Who is protected?

The person giving the medication does not need to be a doctor for double effect to apply. Other health professionals and care givers, including nurses, aged care workers, paid or unpaid carers, or family members may also be protected by double effect so long as there **is medical authorisation and supervision of the medication plan** by a doctor, and death was not intended.

Does the patient need to be close to death?

Double effect is likely to apply only when the patient is near death. In **South Australia**, the legislation applies only where the patient is in the terminal phase of a terminal illness.

Appropriate medication is not euthanasia

A common misconception about palliative medication is that it is the same as euthanasia if it causes the person's death. *'If I give my patient medication and she dies I will have euthanased her'*. Sometimes these concerns have resulted in people not getting enough pain and symptom relief.

Appropriate palliative medication which is intended to relieve pain and suffering is not euthanasia. The law views this as appropriate palliative care and, if the palliative medication also has the effect of hastening the patient's death, protects those providing the medication through double effect.

Pain relief for a person who refuses food and water

Sometimes, a person who is close to death may refuse food and water. This is legal if the person

has capacity to make this decision. **Everyone has the legal right to refuse food and water**, even if this results in their death.

When a **person decides to stop eating and drinking, palliative medication can be given** to reduce any pain or suffering they experience from this.

Key points to remember

1. Giving appropriate palliative medication for pain and symptom relief is lawful in Australia.
2. The doctrine of double effect provides legal protection if a person dies after receiving palliative medication. It applies if the person who gave the medication intended to relieve pain and not hasten death.
3. Double effect will only apply if the medication is administered by a doctor, or by someone else (for example a nurse, aged care worker, carer, family member) under the doctor's supervision; and the person was already close to death.
4. Palliative medication given with the intention of relieving pain and symptoms is not euthanasia.
5. People with capacity have the right to refuse food and drink, even if it results in death. Medication to relieve the person's pain and symptoms can be given in these situations.

If you have concerns about providing palliative medication, ask questions!

Support is available.

- If you work in aged care, discuss your concerns with your manager or the practice nurse.
- If you are a GP, you can seek advice from your medical insurer.

People from diverse social and cultural backgrounds may communicate pain in different ways (including non-verbally). People may also have different views about pain management and using medication such as opioids. It is important to properly inform the person you care for about pain management options and make sure they understand the options.

Learn more about delivering palliative care to:

- Aboriginal people and Torres Strait Islander people at the **Caresearch Aboriginal and Torres Strait Islander Care Hub**. (<https://www.caresearch.com.au/Caresearch/tabid/4146/Default.aspx>)
- People from different social and cultural backgrounds at **PCC4U Culture-Centred Care** (<http://www.pcc4u.org/learning-modules/focus-topics/topic-4-culture-centred-care/>)

Myth-busters: Providing palliative medication

Myth 1: A health professional performs euthanasia or assists dying if he or she provides palliative medication that hastens a person's death

No. *Giving palliative medication in accordance with good medical practice is legal so long as the health professional's intention is to reduce or relieve a patient's pain and suffering, and not to hasten death. This is the case even if the health professional knows death may be hastened by providing the medication. Health professionals are protected by the 'doctrine of double effect'.*

Myth 2: A health professional or other person assists dying by allowing someone to refuse food or drink

No. *If a patient has capacity to refuse food or drink, then respecting their refusal and not force-feeding the person is not assisting them to die.*

Myth 3: The doctrine of double effect will only protect a doctor

No. *In most Australian states and territories a doctor, nurse, carer or family member can give medication and be protected by the doctrine of double effect. Generally though, giving the medication must be ordered or supervised by a doctor. The law in South Australia is slightly different. The medication must be given by the medical practitioner responsible for the person's treatment, or a person supervised by that medical practitioner such as a nurse or carer.*

Medication for Pain and Symptom Relief Case Study



Peter's story

Peter is a 91-year-old resident of the Summer Gardens Residential Aged Care Facility with end stage Non-Small Cell Lung cancer. The cancer has metastasised to Peter's liver and bones, as well as his chest and spine, causing pain, discomfort and shortness of breath. Peter has been receiving therapeutic oxygen via nasal prongs for the last 6 months as his respiratory function has progressively deteriorated. Though he is still alert and can swallow, Peter has lost his appetite and has recently asked the staff to stop bringing him his meals.

On Friday Peter's GP, Hannah, completes her routine visit to the facility. On review, she notes that Peter appears distressed. He complains of unbearable back pain and increased difficulty breathing despite receiving oxygen. Hannah believes the current background dosage of morphine Peter is receiving is no longer effective so she increases this dose on Peter's medication chart. She also requests that the nursing staff administer subcutaneous morphine and/or Midazolam prn to control Peter's pain and reduce his shortness of breath, prescribing them on his medication chart with a dosage frequency of hourly.

Hannah contacts Peter's son Jeffrey to inform him that Peter's condition is deteriorating and that she believes Peter's life expectancy is short, likely days. She explains that she has instructed the staff to provide comfort care to manage Peter's symptoms and ensure he is comfortable at the end of his life.

Early on Saturday morning, Tilda, a Registered Nurse, is on duty. When Tilda visits Peter she notes that he is coughing, moaning and struggling to breathe. He tells Tilda 'I'm in agony', describing excruciating back and chest pain despite having a dose of morphine an hour ago. Following a review of Hannah's instructions in Peter's medication chart, Tilda administers a prn dose of subcutaneous morphine.

An hour later, Tilda checks on Peter. While Peter is more settled than before, he is still moaning and struggling to breathe. Jeffrey, who is visiting Peter, asks Tilda 'Is there anything you can give him? I just want him to be comfortable'. Tilda assesses Peter and in accordance with Peter's medication chart she decides to administer a further dose of prn subcutaneous morphine with a dose of midazolam, to control his pain and breathlessness as optimally as possible. A short time later, Tilda checks on Peter. Although he is now unconscious his breathing has settled and he appears comfortable.

When Tilda returns from her afternoon tea break, a colleague informs her that Peter has just died peacefully. Tilda is worried that the prn medications might have caused his death and fears that she could be held responsible.

Points for reflection

1. Was Tilda's provision of pain and symptom relief to Peter lawful?
2. Has Tilda assisted Peter to die?
3. Before his death, Peter asked the staff not to bring him meals. Was it lawful for him to do so?

Legal considerations on the points for reflection

1. Was Tilda's provision of pain and symptom relief to Peter lawful?

Medication for pain and symptom relief (palliative medication) is important to ease suffering and improve the quality of life of a person with a life-limiting illness.

Sometimes providing palliative medication may have the 'double effect' of relieving pain and suffering as well as hastening a person's death. Where this occurs, the *doctrine of double effect* ('double effect') may apply. Double effect recognises that **giving medication is lawful so long as the intention of the person giving it (e.g. the doctor, nurse) is to relieve the person's pain and suffering and not to cause death.**

Double effect is part of Australian law. Queensland, South Australia, Western Australia and Australian Capital Territory also have legislation that recognises double effect.

Double effect is likely to apply only when the patient's death is imminent. In South Australia, double effect will apply only where the patient is in the terminal phase of a terminal illness.

Double effect can protect doctors, as well other health professionals and care givers including nurses, aged care workers, paid or unpaid carers, or family members, so long as it is medically authorised, there is supervision of the medication plan by a doctor, and death was not intended.

In this case, Peter's death was imminent, and the focus of care was to keep Peter comfortable at the end of his life. Provision of palliative medication was necessary to manage and relieve the symptoms Peter was experiencing. Tilda acted in accordance with Peter's medication chart in which Hannah authorised prn morphine and/or midazolam. Her intention in providing the medication was to relieve Peter's pain and symptoms. She therefore acted lawfully in providing the medication, and is protected by double effect.

Find out more about the law on palliative medication at *End of Life Law in Australia* (<https://end-of-life.qut.edu.au/palliative-care>)

2. Has Tilda assisted Peter to die?

No. A common misconception about palliative medication is that it is the same as euthanasia if it causes the person's death. **Giving palliative medication with the intention of relieving pain and suffering is not euthanasia.** Providing such care is lawful, so long as the health professional's intention is to relieve a person's pain and suffering, and not to hasten death. The medication that Tilda administered to Peter was provided to control and relieve his pain and shortness of breath, and provide comfort. The law views this as appropriate palliative care, not assisting dying.

3. Before his death, Peter asked the staff not to bring him meals. Was it lawful for him to do so?

A person who is close to death will often lose their appetite, and may refuse food and water. If the person has capacity, it is lawful for them to make this decision. **Everyone has the right to refuse food and water even if this accelerates their death.** If the person experiences any pain or suffering as a result of stopping eating and drinking, it is also lawful to provide palliative medication to manage those symptoms.

For further information about the law on providing palliative medication visit the **ELDAC Legal Toolkit's *Medication for pain and symptom relief resources*** (<https://www.eldac.com.au/tabid/4964/Default.aspx>)

Final legal observations

Tilda did not intend for Peter's death to be hastened; rather she gave the prn medication to relieve his pain and breathlessness and provide comfort in accordance with Hannah's instructions. The law would recognise this as appropriate palliative care.

Futile or non-beneficial treatment

Where medical treatment is considered to be futile, non-beneficial or not in a person's best interests, a decision may be made to withhold or withdraw it. However people may disagree about what futility means and when treatment is non-beneficial. This can make these decisions complex. This factsheet explains key legal principles about futile treatment.

Clarifying the law

This factsheet explains:

- What 'futile treatment' is
- Who decides treatment is futile, and how
- When a decision to withhold or withdraw futile treatment can be made
- Health professional's legal obligations regarding futile treatment

What is futile treatment?

People disagree about what 'futile' or 'non-beneficial' treatment means. Common definitions include that it is treatment which:

- is not in the person's best interests,
- cannot achieve its purpose, or
- is not clinically indicated.

An example of futile treatment is providing cardiopulmonary resuscitation to someone who will not respond to it.

'Futile' treatment is not formally defined in law.

Who decides treatment is futile and how do they decide?

Who decides on futility?

A **decision that treatment is futile is generally made by the person's treating doctor**. But it is good practice for health professionals to first discuss this with the person or their substitute decision-maker (where the person lacks capacity). Discussion will help to:

- find out a person's wishes or the substitute decision-maker's understanding of the person's wishes,
- communicate the risks and benefits of continued treatment,
- explain any reasons why the medical team believe treatment is futile, and
- come to a shared view about the options.

In some cases, such as when there is a treatment dispute, **the Supreme Court or a State or Territory Tribunal may be asked to decide if treatment is futile**. However, the courts have usually supported medical assessments about whether or not treatment is futile.

How is futility determined?

There is no easy answer to this question, and no set rules to decide if life-sustaining treatment is futile or inappropriate. Instead, it is generally determined by health professionals on a case-by-case basis. Factors that are usually considered include:

- treatment goals, and the likelihood they will be achieved by providing treatment,
- risks and benefits of further treatment,
- treatment alternatives, and
- the person's prognosis, quality of life, and preferences about palliative care and dying.

When is it lawful to withhold or withdraw futile treatment?

It is lawful in each State and Territory (except Queensland) for a health professional to withhold or withdraw treatment that is futile.

In Queensland, where an adult lacks capacity, consent from a substitute decision-maker is required to withhold or withdraw life-sustaining treatment. This is so even if the treatment is futile. This issue is complex, and health professionals may wish to refer to *End of Life Law in Australia* (<https://end-of-life.qut.edu.au/stopping-treatment/adults/state-and-territory-laws/queensland>) for further information.

Where treatment may be futile, the local guardianship and medical treatment laws about withholding and withdrawing treatment can also apply. The law in this area is complex and it is important to consult the legislation in your State and Territory (<https://end-of-life.qut.edu.au/stopping-treatment>). These laws are also discussed in the Legal Toolkit factsheet 'Withholding and withdrawing life-sustaining medical treatment'.

Does a health professional have to provide futile treatment?

No obligation to treat

Health professionals generally have **no obligation to provide futile treatment** where it would **not be in the person's best interests**, or it is **inconsistent with good medical practice**.

A person and/or their substitute decision-maker **cannot require or demand that a health professional give futile treatment**. An Advance Care Directive also cannot require that treatment be given.

Consent

A health professional **does not need to obtain consent** from a person or a substitute decision-maker to withhold or withdraw futile treatment.

However, as a matter of good medical practice, a person or their substitute decision-maker should always be involved in treatment decision-making, including when health professionals think treatment is futile.

The law in **Queensland is different where a person lacks capacity**. As noted above, the consent of the person's substitute decision-maker is needed.

Disputes about futile treatment

Different views about when treatment is futile can sometimes lead to disputes. Find out more about how to resolve disputes in this kind of situation in your State or Territory at *End of Life Law in Australia* (<https://end-of-life.qut.edu.au/stopping-treatment>).

Key points to remember

1. There are different views about what 'futile treatment' means and this term is not defined in law.
2. Health professionals generally decide whether particular treatment for a person is futile. Sometimes courts or tribunals decide these matters but they generally support medical assessments.
3. There are no universally accepted rules for deciding if treatment is futile but a range of factors relating to the person, their treatment and condition, treatment risks and benefits, and quality of life will be considered.
4. It is generally lawful to withhold or withdraw treatment that is futile.
5. A health professional has no duty to provide treatment that is demanded if it is futile, nor to obtain consent to withhold or withdraw futile treatment. However, the law in Queensland is different.

Myth-busters: Futile and non-beneficial treatment

Myth 1: A health professional must provide life-sustaining treatment to a person if the person's family insists that treatment be provided

No. A health professional generally has no legal obligation to provide treatment they consider to be futile, non-beneficial or not in a person's best interests. This is so, even if family members or substitute decision-makers insist that the treatment be provided.

The law is different though in Queensland where an adult lacks capacity. In this case, consent from a substitute decision-maker is required to withhold or withdraw life-sustaining treatment. This issue is complex, and health professionals may wish to refer to **End of Life Law in Australia** (<https://end-of-life.qut.edu.au/stopping-treatment/adults/state-and-territory-laws/queensland#547985>) or obtain their own legal advice on this issue.

It is always good practice to try to reach a shared decision with the person or their substitute decision-maker about withdrawing or withholding life-sustaining treatment.

Myth 2: Courts will not support a health professional who does not want to provide futile treatment

Courts and tribunals have generally supported medical assessments of futility when these matters are litigated. This is especially so when the health professionals have consulted other health professionals, acted in accordance with guidelines, and engaged in discussions with persons and families.

Myth 3: A health professional or residential aged care facility does not have to provide vaccinations (for example, influenza vaccinations) to residents of these facilities because that would be futile treatment

No. Whether or not treatment is futile can be decided only on a case-by-case basis. This is because it depends on an individual person's needs and whether they would benefit from the treatment (including an assessment of the treatment's benefits and risks). Because of this, it is not possible to make global assessments about futile treatment for people living in residential aged care facilities.

Futile and Non-Beneficial Treatment Case Study



Victor's story

Victor is a 92-year-old with hypertension, Type 2 diabetes mellitus and coronary heart disease. He lives alone and following a recent fall he mobilises using a walking stick. Since his fall he has required assistance with some activities of daily living (showering, housework, meal preparation and shopping) and medication management. To assist his rehabilitation he receives a weekly visit from a Home Care Provider team, and is transported once a week to appointments with a physiotherapist. He has capacity to make decisions about his healthcare, and does not have an Advance Care Directive.

One afternoon Victor experiences chest pain and presses the personal emergency alarm he wears around his neck. His son Patrick is alerted and rushes to Victor's house where he discovers Victor on the floor, unconscious.

Victor is transferred by ambulance to hospital where he is diagnosed as having suffered a cardiac arrest, with several minutes of cerebral hypoxia. He remains comatose, and is placed on artificial ventilation in the Intensive Care Unit (ICU). Within a few days his condition stabilises, but due to the extent of Victor's brain damage and his pre-existing chronic conditions, his specialists consider it is unlikely he will significantly improve, or be able to survive without artificial ventilation.

Dr Hughes, a member of the ICU clinical team, meets with Patrick, and Patrick's wife Claudia, to discuss Victor's prognosis. Dr Hughes explains that the clinical team's unanimous opinion is that continuing to provide ventilation would not be in Victor's best interests as it would be invasive, of little benefit in improving his condition, and may cause him pain and suffering. Patrick asks whether the doctors can continue Victor's life support for a few more days to allow more time for him to show improvement. Dr Hughes clarifies that in the unlikely event Victor did show improvement it would only be minimal, and that even if he could breathe independently he would most likely be immobile, with significant cognitive impairment and care needs. He discusses with Patrick and Claudia withdrawing Victor's ventilation and providing comfort care.

Points for reflection

1. Is it lawful for the clinical team to withdraw Victor's ventilation?
2. If Patrick disagreed with the clinical team's decision and insisted that Victor continue to be ventilated, does that request have to be followed?

Legal considerations on the points for reflection

1. Is it lawful for the clinical team to withdraw Victor's ventilation?

Health professionals generally have **no obligation to provide treatment that would not be in the person's best interests, or is inconsistent with good medical practice.** This type of treatment is known as 'futile' or 'non-beneficial' treatment.

'Futile or non-beneficial treatment' is not defined in law, but is generally used to refer to treatment that is **not in the person's best interests; not achieving its purpose; or not clinically indicated.**

Whether or not treatment is futile or non-beneficial is determined on a case-by-case basis by the person's treating doctor. Factors that may be considered in making this decision include:

- the person's treatment goals and the likelihood they will be achieved by providing treatment;
- the risks and benefits of further treatment;
- treatment alternatives; and
- the person's prognosis, quality of life, and preferences about palliative care and dying.

Dr Hughes and his colleagues consider that continuing Victor's ventilation would be of no benefit, and unlikely to result in significant improvement due to the extent of his injuries and pre-existing conditions. They believe that continuing treatment would carry risks and burdens, including that it would be invasive, and could result in Victor enduring further pain and suffering. They conclude that even if Victor's condition improved and he could breathe without ventilation, his quality of life would be impacted by significant cognitive impairment and immobility, with little prospect of further improvement.

These factors suggest that continuing Victor's ventilation would be futile and non-beneficial. In these circumstances it would be lawful for the clinical team to withdraw Victor's ventilation.

In Queensland however, Patrick's consent would be needed for the clinical team to lawfully withdraw the ventilation. The law on consent and futile and non-beneficial treatment is discussed in the next section.

2. If Patrick disagreed with the clinical team's decision to withdraw treatment, and insisted that Victor continue to be ventilated, does that request have to be followed?

A health professional is not required to provide treatment they consider to be futile or non-beneficial, even if a person, their family member or substitute decision-maker requests that it be provided. A person also cannot require in their Advance Care Directive that futile treatment be given. Therefore, if Patrick requests that ventilation continue, the clinical team has no legal obligation to ventilate Victor if they believe it would be futile or non-beneficial, or not in his best interests to do so.

Similarly, a health professional does not need to obtain consent from a person or a substitute decision-maker to withhold or withdraw futile treatment. However, Queensland law is different when the person lacks capacity. There, a health professional must obtain consent from the person's substitute decision-maker to withdraw or withhold treatment that is considered futile.

The law in Queensland is complex. For further information on Queensland's laws on futile or non-beneficial treatment visit *End of Life Law in Australia*. (<https://end-of-life.qut.edu.au/stopping-treatment/adults/state-and-territory-laws/queensland#547985>)

Though consent is not required (except for in Queensland if the person lacks capacity), it is still good practice for health professionals to involve the person or, if the person does not have capacity, their substitute decision-maker in discussions about futile treatment. This can assist in:

- finding out a person's wishes or the substitute decision-maker's understanding of the person's wishes,
- communicating the risks and benefits of continued treatment,
- explaining any reasons why the medical team believe treatment is futile, and
- coming to a shared view about the options.

If Patrick insisted Victor continue to be ventilated, the clinical team would most likely meet with him again later to try to reach consensus about Victor's treatment, before engaging in other dispute resolution options.

Find out more about managing disagreements about medical treatment decision-making in the *ELDAC Legal Toolkit's Managing disputes about medical treatment decision-making resources*. (<https://www.eldac.com.au/tabid/5281/Default.aspx>)

Final legal observations

The clinical team are able to lawfully withdraw Victor's ventilation on the basis that continuing to provide it would be non-beneficial and futile. They do not require consent to withdraw the ventilation (except in Queensland where Patrick's consent would be required), and may proceed to do so even if Patrick requested that it continue. However, it would be good practice for the clinical team to involve Patrick in discussions about Victor's treatment, and to try to reach consensus. If there is disagreement between Patrick and the clinical team, dispute resolution, such as mediation, could be undertaken.

Emergency medical treatment

There are times when a decision about life-sustaining medical treatment must be made in an emergency. On some occasions there is not enough time to obtain a treatment decision from a person's substitute decision-maker. This factsheet explains the law relating to emergency (or urgent) medical treatment. It also discusses whether a person should be transferred to hospital for emergency treatment.

Clarifying the law

This factsheet explains:

- When emergency treatment can be provided
- Whether consent to that treatment is required, and who can consent
- Whether a person can refuse treatment in an emergency
- The law relating to Resuscitation Plans and orders

When can emergency treatment be provided?

Decisions about emergency treatment occur regularly in aged care, particularly when a person is approaching the end of life. Many of these decisions relate to life-sustaining treatment i.e. treatment that is needed to prolong a person's life. Common examples of this type of treatment in an emergency situation include cardiopulmonary resuscitation, assisted ventilation, and blood transfusions.

In aged care, a decision may also be needed about whether the person should be taken to hospital for emergency treatment (discussed further below).

When consent cannot be obtained

The law about when emergency treatment can be provided if neither a person nor their substitute decision-maker can consent is complex, and differs between States and Territories.

Generally, it is **lawful for a health professional or aged care worker to provide emergency 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.**

The treatment given must be necessary to protect the person's life or health at that time.

When consent can be obtained

It may still **be possible, before emergency treatment is provided, to obtain consent** either from a **person with capacity, or their substitute decision-maker if the person lacks capacity.**

Consent to treatment may also be given before an emergency situation arises e.g. in a person's Advance Care Directive, or noted on a resident's file.

The guardianship and medical treatment decision-making legislation in some States and Territories requires a **health professional to make reasonable efforts (if practical) to find out whether the person has an Advance Care Directive** before giving emergency treatment.

In **South Australia, Western Australia** and the **Northern Territory**, where a person does not have capacity and needs emergency treatment health professionals must **seek consent from the person's substitute decision-maker if it is possible to do so (e.g. a decision-maker can be located and is available and willing).**

Though not required by the legislation of other States and Territories, it is still **good practice to obtain a substitute decision-maker's consent if possible**.

If there is an opportunity to obtain consent and a health professional does not do so, treating the person could result in civil or criminal liability.

For further information about consent to treatment and capacity read the ELDAC factsheet *Capacity and consent to medical treatment*. (<https://www.eldac.com.au/tabid/5270/Default.aspx>).

The law about when emergency treatment can be provided differs throughout Australia. Learn more about the law in your **State or Territory** at *End of Life Law in Australia*. (<https://end-of-life.qut.edu.au/advance-directives/state-and-territory-laws>).

Can emergency treatment be refused?

Emergency 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.

A health professional who provides treatment contrary to a lawful refusal commits an assault on the person.

The guardianship and medical treatment legislation in some States and Territories requires health professionals to consider whether the person has previously refused the emergency treatment.

When a situation is urgent and a health professional does not know whether a refusal of treatment is valid, emergency treatment may be provided while this is being checked.

The law on emergency treatment differs across Australia. Learn more about the law in your **State or Territory** at *End of Life Law in Australia*. (<https://end-of-life.qut.edu.au/stopping-treatment>).

Emergency treatment, and transfers to hospital

In emergency situations it is not uncommon for health professionals or aged care workers to be uncertain about **whether or not an aged care resident should receive treatment, and/or be transferred to hospital**. This dilemma may occur when, for example:

- A **person with capacity** states they do not want to go to hospital, and/or refuses treatment.
- A **person lacks capacity** and their substitute decision-maker:
 - demands treatment be provided, despite an earlier decision that treatment should not be given; and/or
 - instructs an aged care facility to transfer the resident to hospital for treatment, despite previously deciding the resident should not be transferred.

REMEMBER!

Hospital transfers and treatment provided against the wishes of a person (or which is not in their best interests) may result in unwanted, burdensome or non-beneficial treatment, and can cause distress to the person, their family, and health professionals.

Treatment against a person's wishes may be an assault and can also lead to criminal or civil liability for the health professionals involved.

What you can do

Know how to act in an emergency situation by doing the following:

For Aged Care facilities

- **Have a conversation about Advance Care Planning** with the person or their substitute decision-maker upon the person entering aged care.
- **Discuss what treatment the person wants or does not want** if an emergency situation arises.
- If the person wants to **document their end of life decision, learn how this can be done** by reading the *ELDAC Advance Care Directives factsheet* (<https://www.eldac.com.au/tabid/4968/Default.aspx>) or visit *Advance Care Planning Australia* (<https://www.advancecareplanning.org.au/>).
- **If the person already has Advance Care Planning documentation** (e.g. an Advance Care Directive or Resuscitation Plan) **ensure it is properly recorded and can be easily located** by (or is made known to) staff.

For aged care workers and General Practitioners

- **Know your workplaces' policies and procedures** in relation to emergency situations.
- **Know if the residents you care for have an Advance Care Directive, a Resuscitation Plan, and/or substitute decision-maker**, and what the document says about treatment.
- **Respect the person's treatment decision.** Remember that it is lawful for a person with capacity to refuse to go to hospital or to receive life-sustaining treatment even if it will result in their death.

- **Know what the law says about providing treatment** by reading the following *ELDAC Legal Toolkit factsheets* (<https://www.eldac.com.au/tabid/4902/Default.aspx>):

- Capacity and consent to medical treatment
- Advance Care Directives
- Substitute decision-making
- Withholding and withdrawing life-sustaining medical treatment
- Medication for pain and symptom relief for people with a life-limiting illness
- Futile or non-beneficial treatment
- Managing disputes.

Resuscitation Plans and the law

Some States and Territories have **forms to guide clinical decision-making about cardiopulmonary resuscitation (CPR) in emergencies**. Examples include Resuscitation Plans (New South Wales) and Acute Resuscitation Plans (Queensland).

These forms are generally completed by hospital clinicians (following discussions with a person or their substitute decision-maker while a person is in hospital) to communicate whether emergency CPR would be futile or burdensome, or whether the person does not want that treatment.

If a resident has a Resuscitation Plan or similar order which refuses treatment, **whether or not you are required to follow it will depend on the laws of your State or Territory**. For more information read the *ELDAC Advance Care Directives factsheet*. (<https://www.eldac.com.au/tabid/4968/Default.aspx>)

If you are unsure about following a Resuscitation Plan, ask questions!

The law in this area can be complex. If you are unsure about whether or not you should follow a Resuscitation Plan:

- **Aged care workers:** Discuss your concerns with your manager or the practice nurse. They may wish to seek legal advice about the appropriate course of action.
- **General Practitioners:** Seek advice from your medical insurer or your medical defence organisation.
- **Find out more about Resuscitation Plans in your State or Territory** by reading the *ELDAC Legal Toolkit Resuscitation Plan guidelines and resources*. (<https://www.eldac.com.au/tabid/4988/Default.aspx>)

Key points to remember

1. Although the law differs between States and Territories, generally emergency treatment can be given without consent if neither the person nor their substitute decision-maker can provide consent and there is an urgent need for the treatment e.g. to save the person's life, prevent serious damage to health, or prevent significant pain or distress.
2. The law in South Australia, Western Australia and the Northern Territory requires that consent to emergency treatment be sought from a substitute decision-maker if possible (e.g. where a decision-maker is available). It is good clinical practice in all States and Territories to seek consent from a substitute decision-maker if they are available.
3. In some situations it may still be possible to obtain consent to emergency treatment e.g. from a person with capacity. If a health professional could have obtained consent and did not, they may be liable under civil or criminal law.
4. Emergency treatment can be lawfully refused either by a person with capacity; in an Advance Care Directive; or by a person's substitute decision-maker.
5. A person may have a Resuscitation Plan which provides instructions about resuscitation in an emergency. The law on this is complex and will depend on the law in each State and Territory.

Myth-busters: Emergency medical treatment

Myth 1: Emergency treatment cannot be provided to a person who lacks capacity unless a substitute decision-maker consents.

No. *If a person does not have capacity, and it is not possible to obtain consent from the person's substitute decision-maker, the law allows emergency treatment to be given without consent if it is needed urgently to save a person's life, prevent serious damage to health, or prevent significant pain and distress.*

Myth 2: A health professional can provide emergency treatment to a person with capacity without their consent.

No. *If a person has capacity, a health professional or aged care worker must obtain consent from the person prior to providing that treatment, even in an emergency situation. It is only if consent is not possible (for example, the delay to obtain consent would threaten the person's life) that treatment can be given without consent.*

Myth 3: If a person lacks capacity and requires emergency treatment in hospital to save their life, a health professional or aged care worker must arrange to transfer them to hospital for treatment

No. *A person is able (when they have capacity) to refuse treatment, including life-sustaining treatment, even if it will result in their death. A person is also able to refuse to go to hospital if they do not want to receive treatment.*

If a person lacks capacity, a decision about transfer will depend on:

- *whether the person's preferences about hospital transfer or treatment are known (e.g. documented in an Advance Care Directive, or previously stated), or*
- *if they have a substitute decision-maker, the decision of that person.*

The law in Victoria is different. There, consent is not required to transfer a person to hospital in an emergency.

If the person who lacks capacity has previously decided they do not want to receive treatment, their decision should be respected.

If it is not possible to obtain consent to treatment from either a person or their substitute decision-maker, the law allows emergency treatment to be given to save the person's life, prevent serious damage to health, or prevent significant pain and distress. In this case a hospital transfer may occur if it is necessary to enable the person to receive treatment (so long as they haven't previously refused being transferred to hospital).

Emergency Medical Treatment Case Study



Maria's story

Maria is an 87-year-old resident of the Nampara Aged Care Home. She has almost total vision impairment as a result of macular degeneration, and a history of hypertension and breast cancer (in remission). She does not have an Advance Care Directive.

Recently Maria complained to nursing staff that she had nausea, vomiting and abdominal pain. Following medical investigations she was diagnosed with advanced pancreatic cancer. Her oncologist advised that surgery and invasive treatment would be unlikely to significantly improve her condition, and recommended palliative management to control Maria's symptoms and quality of life. On returning to Nampara she was reviewed by Dr Dominic, her GP, and a palliative care plan was established.

One afternoon a few weeks after her cancer diagnosis Maria starts experiencing chest pain. Josef, a nurse on duty at the home, finds her in discomfort reaching for her chest. He is concerned and instructs a colleague to call an ambulance. Maria hears the request for an ambulance and says: 'I don't want to go to hospital. I have made my peace and maybe this is my time'.

The paramedics arrive and examine Maria who repeats her request not to go to hospital. She states that she does not want treatment. The paramedics suspect she is having a non-ST-elevation myocardial infarction and is at risk of cardiac arrest. She requires urgent Percutaneous coronary intervention to treat the narrowing of her coronary arteries, and to save her life. They advise Maria that she may die if she does not receive this treatment immediately but she replies: 'I'm dying anyway, I'm ready to go, I don't want any more treatment.' While the paramedics are confident that Maria has decision-making capacity, they are also worried about her not receiving treatment.

Ultimately, the paramedics decide not to transfer Maria to hospital, and with her consent give her some aspirin and other anticoagulant pain relief to help manage the pain. Maria is transferred back to her room, but continues to experience chest pain. She is reviewed by Dr Dominic, who prescribes further pain and symptom relief. Maria dies the following day, with her family by her side.

Points for reflection

1. Was it appropriate for Maria not to be transferred to hospital, and not to receive urgent medical treatment?
2. If Maria did not have decision-making capacity, could hospital transfer occur and medical treatment be given without her consent?
3. What steps could you take to ensure you know the preferences of the people you care for if they require urgent or emergency treatment?

Legal considerations on the points for reflection

1. Was it appropriate for Maria not to be transferred to hospital, and not to receive urgent medical treatment?

It is not uncommon for health professionals and aged care workers to be unsure about whether to provide urgent medical treatment when a person they care for refuses treatment. This uncertainty can also arise where a person refuses to be transferred to hospital.

Where a person with capacity refuses to go to hospital it is lawful for health professionals not to transfer them, even if they require medical examination and/or treatment urgently, and refusing to go may cause serious harm or death.

Similarly, a person with capacity can refuse medical treatment, including life-sustaining treatment, even if it is clinically indicated and urgently needed (e.g. in an emergency). This is because the law recognises an individual's right to consent or refuse consent to medical treatment, even if it results in an adverse outcome e.g. death.

Transferring a person to hospital or treating them without their consent is considered an assault.

Maria is presumed (by law) to have capacity to make medical treatment decisions. In addition, the paramedics are confident from their examination that Maria has capacity. Therefore, it was appropriate for the paramedics to comply with Maria's lawful refusal and not transfer her to hospital, or provide medical treatment to her, even though it is an emergency situation. It was also appropriate and good practice for the paramedics to seek Maria's consent prior to giving her aspirin and other pain relief.

Visit the **ELDAC Legal Toolkit** for further information on the law about:

- **Capacity and consent to medical treatment** (<https://www.eldac.com.au/tabid/5268/Default.aspx>)
- **Withholding and withdrawing life-sustaining medical treatment** (<https://www.eldac.com.au/tabid/4965/Default.aspx>)
- **Hospital transfers and emergency medical treatment** (<https://www.eldac.com.au/tabid/5273/Default.aspx>)

2. If Maria did not have decision-making capacity, could hospital transfer occur, and medical treatment be given without her consent?

Generally it is lawful for a health professional to provide emergency treatment without consent to a person who lacks capacity if it is needed urgently to save the person's life, prevent serious damage to their health, or prevent significant pain and distress.

Treatment cannot be provided in an emergency if it has been refused by the person in their valid Advance Care Directive. If there is no Advance Care Directive it may still be possible to obtain consent from the person's substitute decision-maker. Indeed, the legislation in some States and Territories requires health professionals to make reasonable efforts (if practical) to seek a substitute decision-maker's consent (and/or to find out whether the person has an Advance Care Directive) before giving emergency treatment. If there is an opportunity to obtain consent and a health professional does not do so, treating the person could result in civil or criminal liability.

If Maria lacked decision-making capacity, the paramedics should find out whether she has an Advance Care Directive that contains a relevant decision about treatment and/or hospital transfer. As she does not have a Directive, the paramedics should consider whether Maria's substitute decision-maker can provide consent.

The law on obtaining a substitute decision-maker's consent in an emergency varies by State and Territory:

- If Maria were in **Western Australia, South Australia** or the **Northern Territory**, the law requires that her substitute decision-maker be contacted to make a decision if it is practical to do so.
- In **Tasmania, Victoria, New South Wales** and the **Australian Capital Territory** a substitute decision-makers' consent would not be required for Maria to be treated or transferred.
- In **Queensland**, Maria could be transferred or treated without a substitute decision-maker's consent if there was an imminent risk to her life or health. However, consent would be needed if the treatment was required to prevent her suffering significant pain and distress.

Though consent may not be required by law in some States and Territories, it would still be good clinical practice in those jurisdictions to try to contact Maria's substitute decision-maker for consent, if time and circumstances permit.

If it were not possible to obtain consent from Maria's substitute decision-maker (e.g. a decision-maker could not be contacted or was not willing to make a decision), the emergency laws in each State and Territory would enable her to be transferred and/or receive medical treatment without consent.

The law on emergency treatment can be complex. For further information visit the **ELDAC Legal Toolkit's *Emergency medical treatment resources*** (<https://www.eldac.com.au/tabid/5273/Default.aspx>)

3. What steps could you take to ensure you know the preferences of the people you care for if they require urgent or emergency treatment?

Knowing the treatment and care preferences of the people you care for can help:

- ensure their treatment preferences are followed,
- prevent unnecessary hospital admissions or provision of treatment that they do not want, or that is not in their best interests, or is futile or burdensome, and
- reduce distress to the person, their family and the health professionals involved in their care.

The **ELDAC Legal Toolkit** contains useful tips for aged care workers, aged care providers and GPs about knowing how to act in an emergency situation. These include:

- Have a conversation about Advance Care Planning with the person or their substitute decision-maker upon the person entering aged care, or receiving home care.
- Discuss what treatment the person wants or does not want if an emergency situation arises.
- Know if the people in your care have an Advance Care Directive or Resuscitation Plan, and what it says.
- Know who the person's substitute decision-maker is (if they do not have capacity), or would be (if they do have capacity), and how to contact them.
- Respect the person's treatment decision.
- Know what the law says about providing, withholding and withdrawing treatment.

For further information and tips, visit the **ELDAC Legal Toolkit *Emergency medical treatment factsheet*** (<https://www.eldac.com.au/tabid/5274/Default.aspx>)

Final legal observations

The paramedics acted lawfully by respecting Maria's competent refusal to be transferred to hospital, and her refusal of an urgent Percutaneous coronary intervention. If Maria did not have decision-making capacity, it would be good practice to seek consent to hospital transfer and medical treatment from her substitute decision-maker, though the law on this varies by State and Territory. If it were not possible to obtain consent from Maria's substitute decision-maker, the emergency laws in those jurisdictions would enable her to be transferred and/or receive medical treatment without consent.

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 arise. This factsheet explores what legal and other avenues are available to manage conflict that arises in aged care about medical treatment decision-making. It focuses on managing disputes between health professionals (or aged care workers) and a person (or their families). It does not address disputes between health professionals or aged care workers.

Clarifying the law

This factsheet discusses:

- How disputes can be resolved within aged care
- If a dispute cannot be resolved, what legal avenues are available
- The role of guardianship bodies, tribunals and courts in medical treatment disputes

Medical treatment disputes in aged care

As a person nears the end of their life, disagreements sometimes occur about their medical treatment. In aged care, these disputes generally arise when there is **disagreement between an aged care worker (or health professional) and a person (or, if the person lacks capacity, their family or substitute decision-maker) about a treatment decision.**

Examples include:

- An aged care worker believes a resident's family or substitute decision-maker is making treatment decisions contrary to the resident's preferences or best interests.
- Conflict with residents or families about types and doses of medication.
- Disputes about hospital transfers, or when medical treatment should be provided.
- Disputes about provision of palliative medication or care.
- Demands from families for treatment to be provided, even if it would be futile or non-beneficial for the person.
- Disputes between family members about who is the person's substitute decision-maker. Learn more about who may be a person's substitute decision-maker by reading the ELDAC factsheet on *Substitute decision-making*. (<https://www.eldac.com.au/tabid/4982/Default.aspx>).

Managing disputes in aged care

Communication about treatment

Communication with the person and their family about future treatment and care, including the person's values and preferences, is essential.

Early, proactive communication can avoid future conflict, and ensure the person's preferences and needs are met.

This can occur by residents, families, aged care workers and health professionals meeting early, preferably when the person enters aged care, to discuss Advance Care Planning.

For practical tips on how to undertake Advance Care Planning with a person visit *Advance Care Planning Australia*.

(<https://www.advancecareplanning.org.au/>).

The person can also choose to record their **treatment decisions and preferences in an Advance Care Directive**. Learn more by reading the *ELDAC Advance Care Directives factsheet*. (<https://www.eldac.com.au/tabid/4968/Default.aspx>).

It is important for aged care workers and health professionals **to involve the person, and their family (provided the person consents) or, if the person lacks capacity, their family or substitute decision-maker in all discussions about the person's care and treatment**. This is particularly important for conversations about withholding and withdrawing life-sustaining treatment or futile treatment. This can achieve consensus about treatment, and allows any problems to be addressed as early as possible.

Wherever end of life conflicts occur, they need to be managed in a timely manner which focuses on the ... best outcome for the patient. Delays and protracted discussions with family may defer decision-making for the patient and prolong the patient's discomfort, distress or pain in the dying phase of their illness.

Executive Summary, *NSW Health Conflict Resolution in End of Life Settings Final Working Group Report*, 2010
(<https://www.health.nsw.gov.au/patients/acp/Publications/conflict-resolution.pdf>).

Preventing disputes

Disputes can also be avoided by aged care organisations and workers:

- **Providing information to residents and their families about palliative care and end of life decision-making**, and the role and obligations of substitute decision-makers.
- **Providing education for staff on recognising a person's deterioration** so appropriate and timely palliative and end of life care can be provided, and families or substitute decision-makers advised.
- **Obtaining the person's medication orders, prescriptions and instructions from the person's GP early** to enable timely access to and administration of end of life care and treatment.
- **Respecting the person's treatment decision**. Remember that it is lawful for a person with capacity to refuse to go to hospital or to receive life-sustaining treatment even if it will result in death.
- **Knowing what the law says about providing treatment** by reading the following ELDAC Legal Toolkit factsheets:
 - Capacity and consent to treatment
 - Advance Care Directives
 - Substitute decision-making
 - Withholding and withdrawing life-sustaining medical treatment
 - Medication for pain and symptom relief for people with a life-limiting illness
 - Futile or non-beneficial treatment
 - Emergency treatment.

What to do if a dispute arises

When a dispute arises, **early resolution can prevent it from escalating. In most situations it is rare for the legal system to become involved**. Most conflict can be managed within the aged care setting by **applying your aged care organisation's complaints or disputes management policies and procedures**.

It is important to **know what those policies or procedures say** so that you can take appropriate action if a dispute arises. This includes knowing who is responsible at each point of the process, relevant timeframes for reporting and addressing complaints, and what documentation must be completed.

Most organisations will require an **aged care worker to advise their Manager as soon as possible about the dispute**. In most cases a Manager will determine the appropriate course of action, based on the nature of the dispute. This action may include:

- Meeting with the aged care worker to obtain information about the dispute;
- Asking an aged care worker to complete a complaint, incident or feedback form outlining the issues; and/or
- Arranging an informal meeting or case conference with the resident or their family to discuss the issues. A formal conference may be arranged for more serious disputes.

Every situation is different, so the action taken will depend on the circumstances, the severity of the issue, and the nature of the medical treatment or care.

When a dispute cannot be resolved, a Manager may advise their Senior Manager or CEO, or seek advice from a lawyer or their State or Territory's guardianship body (i.e. the Public Advocate or Public Guardian).

Practice tip

If you are a GP involved in a dispute, you can also seek advice from your medical insurer or medical defence organisation.

Aged Care Complaints Commissioner

In some cases where there is a dispute a complaint may be made to the **Aged Care Complaints Commission**. (<https://www.agedcarecomplaints.gov.au/internet/accc/publishing.nsf/Content/the-complaints-process>). The Complaints Commissioner is responsible for dealing with complaints about Australian Government funded aged care services. The Complaints Commissioner provides a free service for anyone to raise concerns about the quality of care or services delivered. All complaints are taken seriously and they can be made openly, confidentially or anonymously.

Disputes and the legal system

If a dispute cannot be resolved within the aged care system, the legal system may become involved, including guardianship bodies, or courts and tribunals.

What is the role of guardianship bodies?

Guardianship bodies (such as the Public Advocate or Public Guardian) are independent statutory bodies in each State and Territory. They have powers relating to end of life decision-making for people who lack capacity, and dispute resolution. Aged care workers or health professionals may contact guardianship bodies when:

- a dispute about treatment for a person who lacks capacity cannot be resolved internally;
- they disagree with a decision of a substitute decision-maker;
- there is no substitute decision-maker appointed or available; or
- there is a disagreement about who is the appropriate substitute decision-maker, or a conflict between joint substitute decision-makers.

The powers of guardianship bodies in the States and Territories vary, but they may be able to provide advice about dispute resolution options; mediate disputes; apply to a court or tribunal to be appointed as guardian (if no one else is available or appropriate); or make a treatment decision (in limited circumstances only).

Guardianship laws and the powers of guardianship bodies differ across Australia. Learn more about the law in your State or Territory at *End of Life Law in Australia* (<https://end-of-life.qut.edu.au/stopping-treatment/adults/state-and-territory-laws>), or visit the guardianship bodies' websites using the links on the *ELDAC Legal Toolkit Managing disputes resources page* (<https://www.eldac.com.au/tabid/5285/Default.aspx>).

What can be done if a dispute remains unresolved?

If a treatment dispute remains unresolved, a health professional, aged care worker, the person, their family or substitute decision-maker may apply to a State or Territory tribunal or the Supreme Court for an order.

There is no legal requirement to refer an unresolved dispute to a tribunal or court. However, it is good practice to seek legal advice about this when appropriate (e.g. from an aged care facility's lawyer), and also to tell family or substitute decision-makers about this option.

How do tribunals and courts address medical treatment disputes?

State and Territory tribunals

Tribunals in each State and Territory have powers to decide medical treatment disputes involving adults who lack capacity. These tribunals are like courts but are designed to be quicker, cheaper and easier to use.

The powers of tribunals vary, but they may include:

- deciding whether life-sustaining treatment should be withheld or withdrawn;
- consenting or refusing consent to medical treatment;
- appointing or revoking the appointment of substitute decision-makers; or
- deciding whether or not a person has decision-making capacity.

In making decisions, tribunals must consider a range of factors outlined in State or Territory guardianship and medical treatment legislation. This generally includes the person's best interests, and what the person would have wanted for themselves.

The laws about tribunals and their powers differ across Australia. Learn more about the law in your State or Territory at *End of Life Law in Australia* (<https://end-of-life.qut.edu.au/stopping-treatment/adults/state-and-territory-laws>), or visit the tribunals' websites using the links on the *ELDAC Legal Toolkit Managing disputes resources page* (<https://www.eldac.com.au/tabid/5285/Default.aspx>).

The Supreme Court

The Supreme Court in each State and Territory has broad powers to resolve disputes about medical treatment, and to confirm whether or not providing, withholding or withdrawing treatment would be lawful.

Practice tip

Generally cases are brought before the courts by aged care services rather than individual health professionals or aged care workers. Before instigating court proceedings, legal advice should be sought.

When making a decision a Supreme Court must consider the person's best interests. There are no established criteria for determining this, but the courts will consider factors including:

- medical evidence regarding the person's diagnosis, prognosis and treatment options;
- whether the requested treatment is overly burdensome (so that the burdens of treatment outweigh any possible benefits);
- views and wishes of the person about treatment (and, to a lesser extent, views of the person's family); and
- quality of life of the person if they receive treatment (which the courts have considered particularly when the person has significant cognitive impairment).

In most cases, the courts have agreed with medical opinion about whether or not providing life-sustaining treatment was in the person's best interests. However, this is not always the case.

Key points to remember

1. Most disagreements about medical treatment can be resolved through good communication and timely dispute resolution processes within aged care settings.
2. 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.
3. 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.
4. The State and Territory Supreme Courts also have powers to resolve disputes about medical treatment at the end of life. When making a decision for adults who lack capacity, the Courts' paramount consideration is the person's best interests.

Myth-busters: Managing disputes

Myth: When there is a medical treatment dispute with a resident or their family, a court or tribunal must be involved.

No. *The legal system rarely becomes involved in disputes relating to aged care as most conflict is able to be resolved through communication, and following internal dispute and conflict management policies and processes. If a medical treatment dispute cannot be resolved, the aged care organisation or health professional can seek legal advice, or contact their State or Territory guardianship body (i.e. the Public Advocate or Public Guardian) for information and advice.*

Managing disputes about medical treatment decision-making: Case study

Bill and Rebecca

Bill is an 85 year old with coronary heart disease in residential aged care. Late one Saturday evening Bill feels short of breath and presses the call button for the nurse.

Sarah, a recent nursing graduate, is one of the nurses on duty. She assesses Bill and determines his oxygen saturation is slightly lower than usual. Given Bill has a PRN order for oxygen she administers this and waits 5 minutes before reassessing. Bill tells her his breathing has improved, but he feels a bit dizzy. His oxygen saturation remains low. As it is the weekend, Sarah decides not to inconvenience the home's GP. She tells Bill there is nothing to worry about and that she will check in on him a little later. Her nursing colleagues and the Registered Nurse After Hours Coordinator (RNAHC) are busy dealing with an emergency, and she is unable to discuss Bill with them immediately.

Due to the emergency, Sarah spends the rest of the evening managing other residents mostly on her own. When she checks on Bill a few hours later he is experiencing serious breathing difficulties and cannot communicate. Sarah immediately replaces Bill on the oxygen (as he had removed the mask), and calls an ambulance. The paramedics assess Bill, initiate a higher dose of oxygen, and gain IV access. Bill is transferred to hospital, where a respiratory physician determines Bill has pneumonia.

Rebecca, the facility's RNAHC, contacts Bill's daughter Emily and explains what has happened. Emily is furious that a GP was not called when Bill first experienced breathing problems. She requests a meeting with the facility's management the following day.

Rebecca meets with the Facility Manager and Sarah to discuss the incident. They check the facility's policy on managing deteriorating residents. They conclude that Sarah acted contrary to the policy by failing to escalate Bill's condition to the RNAHC and the GP in a timely manner. She should also have checked on Bill every 30 minutes instead of the hours later. The policy also says training on managing deteriorating residents is to be provided to all staff annually but no training exists. The Facility Manager was unaware of this, having only recently started in her role.

When Emily meets with the Facility Manager and Rebecca they acknowledge that Bill's deteriorating condition should have been escalated to a GP earlier, and apologise to Emily and Bill for their mistakes. The Facility Manager commits to developing best practice training for staff to improve the management of deteriorating residents, as well as improving the existing policy. She also advises they will review and optimise after hours clinical staff to improve service delivery when emergencies arise. Emily appreciates the apology and is satisfied with those proposals. After successful inpatient treatment Bill returns to the facility.

Managing disputes about medical treatment decision-making: Case study

Kim, Linh and Anh

Kim is a 76 year old woman in residential aged care. Five years ago she was diagnosed with late onset schizophrenia, characterised by delusions.

She experiences disorientation, confusion and short-term memory deficits, which have deteriorated further in the past 3 months. She is accommodated in a secure wing at the care facility as she requires constant supervision, and management of her wandering behaviour. Kim receives weekly visits from her granddaughter Linh, and enjoys her company. Linh is satisfied that Kim is receiving appropriate care.

Kim has less regular contact with her brother Anh, who is concerned about Kim's care. He believes that she is isolated unnecessarily, and that the home is understaffed. He has argued with the staff, who he says are denying Kim traditional Vietnamese medicine to manage her health conditions. Kim has a history of paranoid delusions relating to Anh, which have caused her to fear him, and she appears distressed when he visits. Linh and Anh have a history of conflict with each other, and Linh tells Anh to stop contacting Kim. She asks the facility to block Anh's calls.

Health care decisions are required for Kim to ensure she receives appropriate treatment for new health conditions, in particular suspected skin cancers which need to be biopsied and possibly

removed. Kim's GP has advised that due to her cognitive condition Kim is unable to make simple or complex personal decisions, including decisions about health care. Linh and Anh have provided conflicting treatment instructions to the facility and GP due to their lack of consensus.

The facility's Residence Manager is aware that the current decision-making process is ineffective, and arranges a family conference, in accordance with the facility's dispute management policy, to try to reach an agreement about Kim's treatment. During the conference Linh and Anh argue, and Anh becomes frustrated and leaves. As the dispute is unable to be resolved informally, it requires escalation to the State's Civil and Administrative Tribunal for the appointment of a guardian to make health care decisions for Kim.

The Tribunal will determine whether Kim has capacity to make health care decisions. If she does not have capacity (which is highly likely on the facts in this case), the Tribunal would likely appoint a guardian. The Tribunal would determine whether either Linh or Anh are appropriate to be appointed guardians, or whether someone else, such as the Public Guardian, should be appointed. The appointment of a guardian will clarify for the facility's staff and Kim's medical practitioners who is the legally recognised substitute decision-maker for Kim's health care and medical treatment.

Based on: <https://archive.sclqld.org.au/qjudgment/2015/QCAT15-434.pdf>

Overview of voluntary assisted dying

In Australia, laws that legalise voluntary assisted dying (VAD) have been passed in all States: Victoria, Western Australia, Tasmania, South Australia, Queensland, and New South Wales. The laws in each State are similar but there are key differences.

Clarifying the law

This factsheet explains:

- Common features of the laws across States, including eligibility criteria, processes to access VAD, and safeguards
- Obligations of health professionals and institutions in relation to VAD

The information in this factsheet is an overview only. For detailed information about the law on VAD in your State visit *End of Life Law in Australia*. (<https://end-of-life.qut.edu.au/assisteddying>)

What is voluntary assisted dying?

Voluntary assisted dying (VAD) is the assistance provided by a health practitioner to a person with a terminal illness, disease or medical condition to end their life. It includes:

- **self-administration**, where the person takes the VAD medication themselves, and
- **practitioner administration**, where the person is given the medication by a health practitioner.

‘Voluntary’ means it is the person’s voluntary choice. The person must have decision-making capacity to decide to access VAD.

Is voluntary assisted dying legal in Australia?

Laws that allow VAD have been passed in all Australian States.

In **Victoria, Western Australia, Tasmania, Queensland, and South Australia VAD is operating**, and is available in limited circumstances to people who meet the eligibility criteria.

VAD laws will **commence operation in New South Wales on 28 November 2023**. In this factsheet New South Wales’ VAD laws are discussed as though they are already operating.

VAD is illegal in the **Northern Territory** and the **Australian Capital Territory**.

Learn more about the law on VAD at *End of Life Law in Australia*. (<https://www.end-of-life.qut.edu.au/assisteddying>)

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

It is lawful (and good clinical practice) to provide pain relief to manage a person’s pain and symptoms at the end of life.

Learn more about the law on providing pain relief in the **End of Life Law Toolkit factsheet *Legal Protection for Administering Pain and Symptom Relief***. (<https://www.eldac.com.au/tabid/4985/Default.aspx>)

VAD laws in Australian States

The VAD laws in each State are similar, but there are some key differences.

Eligibility criteria

To access VAD **the person must meet all of the eligibility criteria** in their State. A person is eligible if they:

- **are aged 18 years or over;**
- **are an Australian citizen or permanent resident**, who has been resident in the State for at least 12 months when they first request VAD (these criteria can be met in other ways in Tasmania, Queensland and New South Wales);
- **have decision-making capacity** for VAD;
- **are acting voluntarily and without coercion;**
- have an **enduring request** for VAD (i.e. their request is ongoing); and
- have a **disease, illness or medical condition** that is:
 - **advanced and will cause death.** In all States except Tasmania it must also be **progressive** (i.e. the person experiences active deterioration),
 - **incurable** (Victoria, South Australia and Tasmania only), and **irreversible** (Tasmania only),
 - expected to cause **death within six months, or 12 months for a person with a neurodegenerative disease, illness or medical condition.** In Queensland, however, a person expected to die within 12 months may apply for VAD, and
 - **causing suffering that cannot be relieved in a way that the person finds tolerable.** The person's suffering may be physical or non-physical e.g. psychological, existential.

A person will not be eligible for VAD based on having a disability or mental illness (or in New South Wales, dementia) alone – they must meet all of the criteria above to access VAD.

Learn more about the VAD eligibility criteria in your State at *End of Life Law in Australia*. (<https://end-of-life.qut.edu.au/assisteddying>)

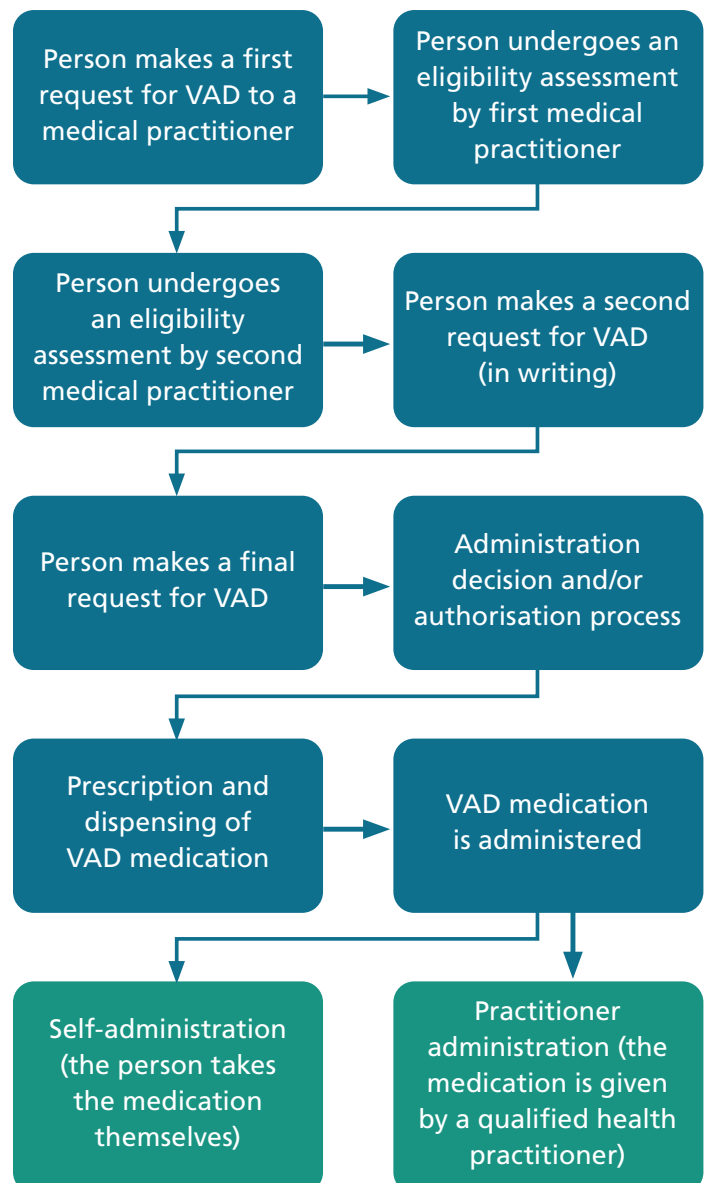
Accessing VAD

To access VAD, each State **requires a person to undergo a request and assessment process.** It generally involves a person:

- making **at least three requests** for VAD; and
- being **assessed as eligible by at least two independent medical practitioners.**

The person can withdraw their request for VAD at any time.

This diagram shows the basic VAD request and administration process in Victoria, Western Australia, South Australia, Queensland, and New South Wales. Tasmania's process is similar but has additional requirements.



The two doctors who assess VAD eligibility must both have undertaken specialised VAD training in the State where they practise.

The process for requesting VAD is different in each State. Learn more about the process in your State at *End of Life Law in Australia*. (<https://end-of-life.qut.edu.au/assisteddying>)

Administration of VAD medication

The **VAD medication can be administered by the person (self-administration), or, in some cases, a health practitioner (practitioner administration)**. The situations in which a practitioner can give the medication, and which health practitioners are permitted to do this differ in each State.

Learn about practitioner administration in your State at *End of Life Law in Australia*. (<https://end-of-life.qut.edu.au/assisteddying>)

The person may take the VAD medication at a time and place of their choosing. Other people (e.g. family and friends) may be present, if the person wishes. There is no requirement for other people to attend, but a witness must be present for practitioner administration in all States except Tasmania.

Safeguards

Each State has safeguards to ensure that VAD is only accessed by eligible people. Some of the key safeguards in all States are:

- **Restrictions on when health professionals can initiate a discussion or provide information** to a person about VAD.
- Requirements in some cases for **additional specialist opinions** to be obtained to determine if a person is eligible for VAD. An example is where it is unclear that a person has capacity.
- Strict protocols governing the **prescription, dispensing and disposal of VAD medications**.

- Any **unused or remaining VAD medication must be returned** (e.g. to the dispensing pharmacist).
- **Offences** for anyone who induces another person to request VAD, or take the VAD medication.
- **Oversight** by independent Boards or Commissions in all States. Their roles include monitoring, reporting, and research.

Legal rights and obligations of health professionals

Health professionals e.g. medical practitioners, registered nurses, allied health professionals, enrolled nurses and personal care workers have rights and obligations under VAD laws.

These differ depending on the person's profession, the State they work in, and whether they choose to be involved with VAD. Some key obligations are discussed here.

Learn more in the End of Life Law Toolkit factsheets *Voluntary assisted dying in aged care: Roles and obligations of medical practitioners, registered nurses, allied health professionals and enrolled nurses, and personal care workers*. (<https://www.eldac.com.au/tabid/7586/Default.aspx>)

Discussing VAD and providing VAD information

There are **restrictions on when VAD can be discussed, and which health professionals can do this**. There are also **restrictions on providing information about VAD**.

Victoria and South Australia

Medical practitioners, nurses and other registered health practitioners cannot start VAD discussions with a person. All health professionals and personal care workers can provide VAD information if the person requests it.

Western Australia, Tasmania, Queensland and New South Wales

In **Western Australia, Tasmania, Queensland and New South Wales**, a medical practitioner can initiate VAD discussions, but must also provide information about treatment and palliative care options. A nurse practitioner in Western Australia and Queensland can also do this.

In **Tasmania**, all registered health practitioners other than a medical practitioner can initiate VAD discussions but must inform the person that a medical practitioner is the best person to discuss VAD with.

In **New South Wales**, all registered health practitioners other than a medical practitioner, other health professionals and personal care workers can initiate VAD discussions but must inform the person that they have palliative care and treatment options available, and should discuss these with the person's medical practitioner.

In all four States, all registered health practitioners and personal care workers may provide information about VAD if a person or resident requests it.

Learn more about the law on discussing VAD and providing VAD information in your State at *End of Life Law in Australia*. (<https://end-of-life.qut.edu.au/assisteddying>)

Participating in VAD

Health professionals e.g. medical practitioners, nurses and allied health professionals working in aged and home care **can decide whether or not to participate in VAD**. Personal care workers can also choose not to be involved with VAD. However, in some States objecting health professionals, as well as non-participating residential facilities e.g. RACFs, nursing homes still have certain legal obligations.

Conscientious objection by health professionals

Health professionals can conscientiously object to participating in VAD.

Personal care workers can also choose not to be involved with VAD. In all States they may refuse to:

- accept a VAD request;
- participate in VAD assessment processes or administration decisions;
- prescribe, supply or administer a VAD medication; or
- be present during administration of VAD medication.

In Victoria, South Australia, Queensland, and New South Wales, a person with a conscientious objection can also refuse to provide information about VAD.

In Western Australia, Queensland and New South Wales, a medical practitioner who refuses to accept a first request for VAD because of a conscientious objection must let the person know immediately. In Western Australia, Tasmania and Queensland, they must also provide contact details of a service which provides VAD assistance.

The obligations of health professionals who conscientiously object to VAD differ in each State. Learn more about the law in your State at *End of Life Law in Australia*. (<https://end-of-life.qut.edu.au/assisteddying>)

Participation by RACFs and other institutions

Generally, institutions such as **residential facilities may decide whether to provide VAD, and what level of support they offer to residents seeking VAD**. The laws differ in each State.

Victoria, Western Australia and Tasmania

The VAD laws do not discuss institutional participation in VAD. Institutions including residential facilities may decide what level of involvement they have.

South Australia, Queensland and New South Wales

Institutions may choose not to participate in VAD. However, **residential facilities who decide not to participate have certain obligations so that a resident can access VAD if they wish.**

The law on institutional obligations relating to VAD is complex. Learn more in the *End of Life Law Toolkit* factsheets *Voluntary assisted dying in aged care: Residential facilities in Victoria, Western Australia and Tasmania* and *South Australia, Queensland and New South Wales*. (<https://www.eldac.com.au/tabid/7586/Default.aspx>)

Key points to remember

1. In Victoria, Western Australia, Tasmania, Queensland, and South Australia VAD is operating, and is lawful in limited circumstances. VAD will become lawful in New South Wales on 28 November 2023.
2. To be eligible to access VAD, a person must meet a range of criteria including:
 - they are an adult with decision-making capacity;
 - they have a disease, illness or medical condition which will cause death within 6 months (12 months in Queensland and in other States for a neurodegenerative disease); and
 - their condition is advanced, and is causing intolerable suffering. In all States except Tasmania the condition must also be progressive.
3. To access VAD, a person must undergo a request and assessment process that includes making (at least) three separate requests for VAD, and eligibility assessments by (at least) two independent medical practitioners.
4. The VAD medication will be administered either by the person (self-administration) or by a health practitioner (practitioner administration).
5. A range of safeguards apply to the VAD process, including requirements relating to oversight and reporting, and prescription, disposal and safe storage of VAD medication.
6. There are restrictions on when health professionals can discuss VAD or provide VAD information to a person, and which health professionals can do so.
7. Health professionals can conscientiously object to participating in VAD, but in some States they will still have legal obligations to ensure patients and residents can access VAD.
8. Generally institutions e.g. RACFs and hospitals may decide whether to provide VAD, and the support they offer those wanting to access VAD. Institutions in South Australia, Queensland and New South Wales have specific obligations to allow people to access VAD if they wish.

For more information about VAD laws and policies in Australia visit:

- ELDAC End of Life Law Toolkit factsheets: *Voluntary assisted dying in aged care*:
 - *Roles and obligations of medical practitioners, registered nurses, allied health professionals and enrolled nurses, and personal care workers* (<https://www.eldac.com.au/tabid/7586/Default.aspx>)
 - *Residential facilities in South Australia, Queensland and New South Wales and Victoria, Western Australia and Tasmania* (<https://www.eldac.com.au/tabid/7586/Default.aspx>)
 - *Frequently asked questions about voluntary assisted dying* (<https://www.eldac.com.au/tabid/7410/Default.aspx>)
- *End of Life Law in Australia* (<https://end-of-life.qut.edu.au/assisteddying>)
- State departments of health (<https://www.eldac.com.au/tabid/5756/Default.aspx>)
- End of Life Law for Clinicians online Module 11: Voluntary assisted dying (<https://palliativecareeducation.com.au/course/index.php?categoryid=5>)