ELDAC
End of Life Directions for Aged Care

Frequently asked questions about common end of life legal issues in aged care

This factsheet is for health professionals working in aged care, aged care providers, and older people receiving aged care. ***Older person*** *is used to refer to people receiving aged care services in a residential care home, as well as in a home or community setting.*

Voluntary assisted dying is a new end of life choice and practice. For frequently asked questions about voluntary assisted dying, read the End of Life Law Toolkit factsheet ***Frequently asked questions about voluntary assisted dying***. (https://www.eldac.com.au/Our-Toolkits/End-of-Life-Law/Voluntary-Assisted-Dying/FAQs)

Dignity of risk and decision-making

What is dignity of risk and how does it relate to end of life decision-making?

Dignity of risk is an important part of an individual's dignity at the end of life. This means older people have the right to make decisions and take personal risks, even if their choices may result in personal harm. Examples include where an older person at the end of life:

- refuses transfer to hospital for treatment, even if this may cause harm or death.
- refuses CPR, even if this may result in death.
- has swallowing difficulties but chooses to eat certain foods, even if it may cause choking.
- refuses to eat or drink.

The Aged Care Quality Standards require aged care providers to support older people to exercise dignity of risk, choice, autonomy, and independence in decision-making.

Learn more about managing risk in the ELDAC Managing Risk Toolkit. (https://www.eldac.com.au/Our-Toolkits/Managing-Risk)

Consent to medical treatment

When is consent to medical treatment needed?

Consent is required before an older person receives medical treatment or undergoes a medical examination. Consent is also needed to **transfer an older person to hospital**.

If consent is not obtained, the treating health professional could be liable under civil or criminal law, and is at risk of disciplinary action.

Consent is valid only when:

- the older person has **decision-making capacity**,
- they give consent **freely and voluntarily**, and
- the **consent relates to the proposed treatment**.

If the older person does not have capacity, they may have an Advance Care Directive providing consent, or a substitute decision-maker may consent.

There are some limited situations where consent to medical treatment is not required e.g. in an emergency. This is discussed further below.

Learn more about consent in the End of Life Law Toolkit factsheets.

- *Overview: Capacity and Consent to Medical Treatment.* (https://www.eldac.com.au/Our-Toolkits/End-of-Life-Law/Capacity-and-Consent-to-Medical-Treatment/Overview)
- *Consent to medical treatment: A guide for aged care providers.* (https://www.eldac.com.au/Portals/12/Documents/Factsheet/Legal/Consent-to-medical-treatment_A-guide-for-aged-care-providers.pdf)

When will consent be 'free and voluntary'?

Consent will be free and voluntary if the **older person is choosing to give consent without any pressure or coercion from another person**.

Appropriate advice and decision-making support from family, support networks or health professionals is allowed so long as the older person is still making the decision they want. However, it is important to be alert to signs that an older person might be experiencing pressure to decide in a particular way. Signs can include:

- an older person changing their treatment decision when a particular person is present.
- someone encouraging an older person to decide in a particular way that suits their own interests.
- someone preventing an older person from making their own decision.
- signs of domestic violence or elder abuse, whether physical, emotional, psychological, or financial.

If you are concerned that an older person you care for is experiencing pressure, coercion, domestic violence or elder abuse, discuss this with your manager or provider.

In an emergency, is consent needed to give treatment to an older person?

This depends on whether the older person has decision-making capacity (capacity). Sometimes in an emergency an older person may still have capacity. In this case, the older person's consent is required before treatment can be given, or for transfer to hospital.

Generally, if the older person does not have capacity, urgent treatment can be given and transfer can occur without consent if:

- **there is no Advance Care Directive refusing the treatment or transfer**,
- **it is not possible to obtain consent from the older person's substitute decision-maker**, and
- **treatment or transfer is needed urgently** to save the person's life, prevent serious damage to their health, or prevent significant pain and distress.

In some States and Territories other requirements must also be met.

For information about the law on urgent medical treatment in your State or Territory, visit *End of Life Law in Australia* Treatment Decisions webpage and scroll to '*Urgent medical treatment*' (https://end-of-life.qut.edu.au/treatment-decisions/adults/state-and-territory-laws)

Capacity and decision-making

Who can make decisions about an older person's medical treatment?

This depends on whether the older person has decision-making capacity.

Everyone is presumed to have capacity unless there is evidence that they do not. **A person with capacity can make their own medical treatment decisions**. They can consent to or refuse medical treatment, even if treatment is needed to keep them alive.

If an older person does not have capacity, they may have made an Advance Care Directive that gives directions about treatment, or a substitute decision-maker may decide.

Paid carers, residential care homes, and health professionals cannot consent to medical treatment for older people (though there is an exception in **South Australia**).

Learn who can be a substitute decision-maker in the End of Life Law Toolkit factsheet *Substitute decision-making*. (https://www.eldac.com.au/Our-Toolkits/End-of-Life-Law/Substitute-Decision-Making/Factsheet)

When will an older person have decision-making capacity to make their own treatment decisions?

An older person will have capacity to make medical treatment decisions 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.

Each State and Territory has its own 'legal test' for health professionals to apply to decide whether an older person has decision-making capacity.

Learn the test for decision-making capacity in your State or Territory at *End of Life Law in Australia*. (https://end-of-life.qut.edu.au/capacity#statetercap)

Who decides if an older person has capacity to make their own treatment decisions?

A **doctor or other health practitioner** (e.g. psychologist) with relevant expertise can assess whether an older person has decision-making capacity. If there is a dispute about an older person's capacity, a court or tribunal may be able to decide. Legal advice should be sought before making an application for a court or tribunal to decide capacity.

Can an older person have capacity for some decisions but not others?

Yes. An older person might have capacity to make some decisions but not others, depending on the decision. For example, an older person may have capacity to make simple decisions e.g. whether to have paracetamol for pain relief, but not more significant decisions e.g. whether to have knee surgery. An older person's capacity to decide must therefore be considered every time a decision is needed.

Can an older person have capacity at some times but not others?

Yes. An older person may have fluctuating capacity, meaning they may have capacity at certain times but not others. This is common in older people with dementia or mental illness. Or, an older person might temporarily lose capacity due to a medical condition e.g. a UTI causing delirium, or being unconscious.
A person's capacity must therefore be judged at the time a treatment decision is required.

Can an older person with dementia make their own medical treatment decisions?

Yes, so long as they have decision-making capacity. Having dementia, or another impairment, condition, illness or injury, does not mean that a person lacks capacity to make medical treatment decisions. An older person with dementia is presumed to have decision-making capacity unless it can be shown that they do not. The test for whether a person with dementia has capacity is the same as for everyone else (see *When will an older person have decision-making capacity?* above).

If it is not possible for an older person with dementia to decide independently, they may still be able to decide with appropriate support (supported decision-making).

Learn about capacity and dementia in the End of Life Law Toolkit factsheet *Overview: Capacity and Consent to Medical Treatment*. (https://www.eldac.com.au/Our-Toolkits/End-of-Life-Law/Capacity-and-Consent-to-Medical-Treatment/Overview)

Can an older person make a treatment decision that their health professional or family disagrees with?

Yes. An older person with decision-making capacity has the right to make any decision they wish. Their decision must be respected, even if others do not agree, or it may result in death e.g. refusing life-saving medical treatment such as CPR. Respecting the older person's decision supports their dignity of risk. Refusal of treatment should be clearly documented in the older person's records.

Can an older person refuse to eat and drink?

Yes. An older person with decision-making capacity has the right to choose not to eat or drink or to be artificially fed or hydrated. Respecting an older person's choice supports their dignity of risk. Supporting a person who chooses not to eat or drink is not voluntary assisted dying.

Even if the person does not have decision-making capacity, they may still be able to indicate their preferences about eating and drinking, or be supported to make decisions about this. These preferences should be respected.

If an older person does not have capacity, should they still be involved in decision-making?

Yes. All older people have the right to participate in decisions about their treatment, including people with dementia and other cognitive impairment. **Even if an older person does not have capacity, they should be supported to participate in decision-making**. In some cases, an older person may still be able to make decisions with appropriate support.

Learn more about supported decision-making:

- in the End of Life Law Toolkit factsheet *Substitute decision-making*. (https://www.eldac.com.au/Our-Toolkits/End-of-Life-Law/Substitute-Decision-Making/Factsheet)
- at *End of Life Law in Australia*. (https://end-of-life.qut.edu.au/treatment-decisions/adults#supporteddecisionmaking)

Advance Care Directives

Does an older person need to have an Advance Care Directive?

No. Making an Advance Care Directive is voluntary. An older person can choose not to have a Directive if they wish. An older person cannot be refused residence in a residential care home because they do not have a Directive, or do not want to make one.

Can an older person without capacity make an Advance Care Directive?

No. The older person must have decision-making capacity to make an Advance Care Directive.

Can family members make an Advance Care Directive for an older person?

No. Family members and substitute decision-makers cannot make an Advance Care Directive for an older person. Only the older person can make the Directive.

Can an Advance Care Directive be followed when an older person has capacity?

No. An Advance Care Directive can only be followed when an older person no longer has capacity to make their own decisions about medical treatment. The **Australian Capital Territory** is an exception, as a Health Direction may apply when an older person still has capacity.

If the older person has capacity, you should speak with them directly about their treatment preferences and obtain their consent before providing treatment.

When must an Advance Care Directive be followed?

An Advance Care Directive will be **valid and must be followed** by health professionals, families and substitute decision-maker if it:

- **was made voluntarily by the older person, when they had decision-making capacity**,
- **meets the State or Territory's formal legal requirements**, and
- **gives directions about the specific treatment proposed**.

In **Queensland**, there are further legal requirements that must be met before a health professional can follow an Advance Health Directive that refuses life-sustaining treatment.

Some States have binding (must be followed) and non-binding directions in Advance Care Directives:

- In **Victoria**, an Instructional Directive is binding and must be followed by health professionals.
- In **South Australia**, an Advance Care Directive that refuses specific treatment, including life-sustaining treatment, is binding and must be followed.
- In **Tasmania**, a clear and unambiguous refusal or withdrawal of particular health care is binding and must be followed.

In these States, non-binding sections of Directives should still be followed by health professionals if possible. These sections generally discuss a person's values and preferences about their health care, and can help inform decision-making by health professionals and substitute decision-makers.

If you work in Queensland, Victoria, South Australia, or Tasmania, learn more about following Advance Care Directives at *End of Life Law in Australia*. (https://end-of-life.qut.edu.au/advance-care-directives/state-and-territory-laws)

Can a family member or substitute decision-maker 'override' an older person's valid Advance Care Directive if they disagree with it?

No. An older person's valid Advance Care Directive must be followed, even if others disagree with it. Substitute decision-makers and families have no power to overrule an older person's Directive.

Are there times when an Advance Care Directive can't be followed?

In some rare situations, there are exceptions to following a Directive. For example, an older person's circumstances or views might have changed significantly since they made the Directive, and they would no longer intend it to apply. In this situation, a health professional does not have to follow the Directive, as it will no longer be valid.

Other exceptions to following Advance Care Directives are discussed at *End of Life Law in Australia*. If you are uncertain about whether an older person's Directive should be followed, speak to your manager, or your provider could seek legal advice.

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

Life-saving treatment and hospital transfers

If a family member or substitute decision-maker requests life-saving treatment for an older person, does it have to be given?

No. Health professionals have no legal obligation to provide treatment if it is not in the older person's interests, would be of no benefit, cannot achieve its purpose, or is inconsistent with good clinical practice. An older person, substitute decision-maker, or family member cannot demand that life-saving treatment e.g. CPR, or any other treatment, be given if it would be non-beneficial or futile.

If an older person refuses to go to hospital, do I have to follow their decision?

Yes, so long as they have decision-making capacity. An older person with capacity has the right to refuse hospital transfer. Dignity of risk means that an older person can refuse transfer even if they may experience harm or will die without treatment.

If the older person does not have capacity and transfer is needed urgently (discussed above, see *In an emergency, is consent needed to treat an older person?*), it is lawful to transfer the older person to hospital without consent.

If it is not an emergency and the older person has impaired capacity, then consent for transfer must be sought from the person's substitute decision-maker.

Does a health professional or aged care provider have to transfer an older person to hospital if requested to by family members?

No. Family members and substitute decision-makers cannot require aged care providers to transfer an older person to hospital if the older person's treating health professional believes **transfer would be non-beneficial, burdensome or futile**, even in an emergency.

There is also no requirement to transfer if:

- the older person has capacity, refuses to be transferred, and family members disagree with the refusal, or
- the older person no longer has capacity and has refused transfer in their Advance Care Directive.

It is an assault for a person to be treated against their wishes.

Learn more about hospital treatment, transfer and consent in the **End of Life Law Toolkit factsheets**:

- *Urgent medical treatment.* (https://www.eldac.com.au/Our-Toolkits/End-of-Life-Law/Urgent-Medical-Treatment/Factsheet)
- *Consent to medical treatment: A guide for aged care providers.* (https://www.eldac.com.au/Portals/12/Documents/Factsheet/Legal/Consent-to-medical-treatment_A-guide-for-aged-care-providers.pdf)

Managing disputes

If there is disagreement between family members about treatment, whose decision should be followed?

The law in each State and Territory sets out, in order of priority, who can make decisions if an older person does not have capacity. A person who is listed in records as the 'next of kin' will not necessarily be the substitute decision-maker. Visit ***End of Life Law in Australia*** and select your State or Territory to view who can decide (https://end-of-life.qut.edu.au/treatment-decisions).

Most conflict between family members, or between multiple substitute decision-makers, can be resolved through good communication and timely dispute resolution processes. Informal meetings and case conferences can be held to explore the issues and try to reach a shared decision. In most situations, the issues can be resolved without the need for a court or tribunal to become involved.

If shared decision-making is not possible, your provider may wish to seek legal advice. In some States and Territories, the Public Advocate or Guardian may also be able to assist with dispute resolution.

For tips on how to manage disputes in aged care visit the **End of Life Law Toolkit factsheet** ***Managing disputes about medical treatment decision-making***. (https://www.eldac.com.au/Our-Toolkits/End-of-Life-Law/Managing-Disputes-about-Medical-Treatment-Decision-Making)

What can I do if I'm worried that a family member or substitute decision-maker is not acting appropriately?

When making medical treatment decisions, generally family members and substitute decision-makers must consider what decision the older person would have made if they had capacity, and the older person's interests and wellbeing. If you believe that this is not occurring, or they are acting inappropriately or making poor or unusual decisions, you should discuss your concerns with your manager or provider.

If the concerns cannot be resolved through discussion with family members or the decision-maker, you can contact the Public Guardian or Public Advocate in your State or Territory for support and/or advice, or your provider or service can seek legal advice.

Sometimes, a tribunal or court might be needed to resolve the issue by, for example, directing the substitute decision-maker to make a certain decision, or appointing an alternative substitute decision-maker.

Pain relief

Can a family member or substitute decision-maker refuse pain relief for an older person?

It is always good practice to provide pain relief to manage an older person's pain and symptoms at the end of life. Unless an older person has refused pain relief, it should be provided where clinically appropriate.

When making decisions, the law requires that substitute decision-makers consider the older person's values and preferences and promote their wellbeing. This includes consenting to pain management if the older person does not have capacity, would not have objected to having pain relief, and it is clinically recommended.

The legislation in some States and Territories prohibits a substitute decision-maker from refusing palliative care for a person with impaired decision-making capacity. These laws allow health professionals to provide pain relief without consent (though they must first consider the person's preferences and values, and consult with the older person's decision-maker).

For further information, visit ***End of Life Law in Australia*** **Legal Protection for Providing Pain and Symptom Relief** webpage. (https://end-of-life.qut.edu.au/pain-relief)

Will a health professional be legally responsible if they give pain and symptom relief to an older person close to death and they die soon after?

No. A health professional will not be legally responsible in this situation so long as when they gave the pain relief medication, **their intention was to relieve the older person's pain and symptoms, not hasten or cause death**. This legal protection is known as the doctrine of double effect. For this protection to apply, the older person must be near death. The medication must also be prescribed and administered by a doctor or nurse practitioner or administered under that practitioner's orders.

Learn more in the **End of Life Law Toolkit factsheet** ***Legal Protection for Administering Pain and Symptom Relief***. (https://www.eldac.com.au/Our-Toolkits/End-of-Life-Law/Legal-Protection-for-Administering-Pain-and-Symptom-Relief)

For more information

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