

how should care be delivered at the end of life?

information for patients
and their families and carers



introduction

The way that we look after people who are dying is important. Good care at the end of life can help to reduce distress and grief for the person who is dying and for their family, friends and carers.

Doctors, nurses and others working in hospitals do what they can to make sure that people get the best possible care at the end of life. But sometimes the care that is provided is not as good as it could be. Many family members, carers and clinicians have had experience of this.

If you are a patient, family member, carer, consumer or consumer advocate, this information sheet will give you useful information about how care should be provided to people at the end of life in hospitals.

This information sheet supports the *National Consensus Statement: essential elements for safe and high-quality end-of-life*. The Consensus Statement is the result of work by the Australian Commission on Safety and Quality in Health Care to reach agreement about the way care should be provided at the end of a person's life. The Consensus Statement actions are based on evidence, expert knowledge, and the experiences of patients, families and carers.

When this information sheet talks about clinicians, it means trained health professionals such as doctors, nurses, occupational therapists and social workers.



how care should be delivered at the end of life

Ten elements are required for safe and high-quality end-of-life care. Following is a summary of what each element means for you as a patient, and for families, carers and consumers.

1. patient-centred communication and shared decision making

You are supported to make decisions about your care to the extent that you want to.

When clinicians communicate with you, they try to understand your wishes and preferences about your care at the end of life.

Clinicians talk to you openly, honestly and in a way that you can understand about your medical situation and care.

You have the opportunity to have multiple conversations with clinicians about your care at the end of life.

2. teamwork and coordination of care

Your clinicians work together as a team so that you get the best possible care.

You, and your family, carers and substitute decision-maker are part of the team for your care.

You are told about who is responsible for leading and coordinating your care, and the roles and responsibilities of other team members.

The clinicians in hospital work with the people who look after you in the community, such as your GP.

3. components of care

You are always treated with dignity, respect and compassion.

Clinicians ask you, and your family and carers about what is important in your life and your wishes for your future care.

As much as possible, these wishes are taken into account when care is provided.

You have the right to refuse medical treatments.

Clinicians avoid providing treatments that will not help.

You continue to receive care that keeps you comfortable and fits with your wishes, even after other treatment stops.

4. use of triggers to help recognise patients approaching the end of life

Clinicians look at your situation and condition. Based on this, they may talk to you about end-of-life care.

Having early and repeated conversations about end-of-life care is useful; it does not necessarily mean that you will die soon.

You can start to talk to your family and carers about your wishes for your end of life before you are in hospital.

5. response to concerns

You can raise concerns about your care at the end of life and have these concerns addressed.

If you are distressed in any way, you receive rapid assistance from clinicians who can reduce your suffering.

If you, or your family or carers disagree with clinicians about your care, there is a process to manage this, including getting a second opinion.

If disagreements about your end-of-life care are complicated, it may be necessary to ask an independent person for help.

6. leadership and governance

Health services have processes in place to make sure that care for people at the end of life is always safe and of high quality.

There are people throughout the health service who are responsible for end-of-life care.

Health services make sure that their processes for providing end-of-life care work and are available for all patients.

7. education and training

Clinicians and others know how to provide the best possible care to people at the end of life.

8. supervision and support for interdisciplinary team members

Dealing with death and dying can be difficult. Health services ensure that there are processes for clinicians and others to be supervised and supported to prevent burnout and chronic stress.

9. evaluation, audit and feedback

Health services look at the way they provide end-of-life care to see whether this care is safe and of high quality.

Feedback from families and carers is part of this process.

10. systems to support high-quality care

Health services ensure that there are processes in place so that people at the end of life always get safe and high-quality care.

Health services aim to improve end-of-life care, where possible.

Processes for end-of-life care align with best practice and nationally agreed standards.



how you can be involved

It is important that you are involved in making choices about your care at the end of life. This means working with clinicians to understand your situation, thinking about who you would like to be involved in making decisions about your care, and nominating someone to speak for you if you are no longer able to communicate for yourself.

decision-making about care at the end of life

You, and your family and carers can participate in discussions and decision-making with your clinicians about what happens at the end of your life. Alternatively, you might prefer to leave decision-making to your clinicians.

Either way, you might want to think about appointing a substitute decision-maker (often a trusted family member or friend) who can act for you if there is a time when you are no longer able to speak for yourself.

Depending on where you live, a substitute decision-maker may also be called an enduring guardian or enduring power of attorney.

advance care planning

The clinicians looking after you may ask if you would like to make an advance care plan. An advance care plan sets out your wishes for care if you are no longer able to speak for yourself. You can prepare an advance care plan before you enter hospital. Talking to your family or your GP is a good way to start this process.

If you have not already done so, you may wish to talk to your family about your wishes about organ and tissue donation.

making decisions if I can't speak for myself

If you have an advance care plan, this will help to guide the decisions of the clinicians who are providing your care. You can also appoint a substitute decision-maker to speak for you.

If you do not have an advance care plan or a substitute decision-maker, there is legislation in the state or territory where you live that will determine who can speak for you.

If you are no longer able to make your own decisions, your substitute decision-maker, family and carers will work with the clinicians looking after you to make decisions about your care.

where you can get more information

National Consensus Statement: essential elements for safe and high-quality end-of-life care

The Consensus Statement and this guide are available from the Australian Commission on Safety and Quality in Health Care.

www.safetyandquality.gov.au/endoflifecare

advance care planning

Many web sites have information about advance care planning. States and territories have different legislation and ways of dealing with advance care plans. A good place to start is the Advance Care Planning Australia web site, which has links to information that is relevant for each state and territory.

www.advancecareplanning.org.au

Alzheimer's Australia has developed a web site about planning ahead so that your choices will be known if you are not able to express these choices later in life.

www.start2talk.org.au

MyValues is a web site that guides you through a series of statements to help you identify, consider and communicate your wishes about the medical treatment you would want in the later stages of life. It generates a report based on your responses, which you can share with others about your wishes and values. The web site was developed by Barwon Health, funded by the Victorian Department of Health.

www.myvalues.org.au/

carers

Carers Australia is the national body representing carers. The web site includes links to the carers association in your state or territory, which will have links to local services and supports.

www.carersaustralia.com.au

palliative care

Palliative Care Australia is the national body that supports and promotes quality care at the end of life for everybody. The web site includes resources for consumers, patients, family members and carers. Palliative Care Australia has also developed the National Palliative Care Service Directory to help members of the community and clinicians to access information about palliative care services, primary care services that provide care at the end of life, and a range of other services that provide support to people with life-limiting illness.

www.palliativecare.org.au

organ and tissue donation

In Australia, many organisations are involved in improving organ and tissue donation, and the process for donation is coordinated at a national level. The DonateLife web site contains information for people in the community, including fact sheets about having conversations about organ and tissue donation.

www.donatelife.gov.au



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Disclaimer

The National Consensus Statement: essential elements for safe and high-quality end-of-life care describes suggested practice for the provision of end-of-life care in settings where acute care is provided. It is a guiding document designed to inform clinicians and others of recommended practice. The Consensus Statement is not a legal document, and clinicians must continue to be aware of, and abide by, the laws of the jurisdiction in which they practise. Any inconsistency between the Consensus Statement and a law of a state, a territory or the Commonwealth will be resolved in favour of the relevant law.

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