

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.
- When clinicians communicate with you, they endeavour 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 suitable decision-makers are part of the team for your care.
- You are told about who is responsible for leading and coordinating your care, and the role 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 treatments stop.

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 your 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

- St Vincent's Private Hospital has processes in place to make sure that care for people at the end of life is always safe and of high quality.

7. Education and training.

- Our 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. St Vincent's Private Hospital ensures that there are processes for clinicians and others to be supervised and supported to prevent burnout and chronic stress.

9. Evaluation, audit and feedback

- St Vincent's Private Hospital looks at the way we 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

- St Vincent's Private Hospital ensures that there are processes in place so that people at the end of life always get safe and high-quality care.
- We aim to improve end-of-life care in line with best practice and nationally agreed standards.

11. Spiritual Support

- Spiritual support through pastoral care is available. Please advise staff if blessing of the sick is required and/or a visit from clergy is desired.

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 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 advanced care plan (ACP). An ACP sets out your wishes for care if you are no longer able to speak for yourself. You can prepare an ACP 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 ACP, 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 ACP or a substitutive 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

Advanced Care Planning

Many websites have information about advanced 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 website, which has links to information that is relevant for each state and territory.

www.advancecareplanning.org.au

Alzheimer's Australia has developed a website 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 website that guides you through a series of statements to help you identify, consider and communicate your wishes about medical treatment you would want in later stages of life.

It generates a report based on your responses, which you can share with others about your wishes and values. The website 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 website 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 website 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 organizations are involved in improving organ and tissue donation, and the process for donation is coordinated at a national level. The Donate Life website contains information for people in the community, including fact sheets about having conversations about organs and tissue donation.

www.donatelife.gov.au