IRT Group Advance Care Planning - ACT

Information Pack

October 2021

Dear resident, family and friends

At IRT, we encourage our residents and customers to plan for their future health and care needs to ensure their values and preferences are respected and honoured. We've put together some information to help you and your family consider advance care planning, if you haven't already done so.

Advance care planning is the process of enabling a person to record their wishes, values, life goals and preferred outcomes or directions about care. This is particularly important if you are frail, have a chronic illness, multiple diseases, an early cognitive impairment, or are approaching the end of your life. IRT can help guide you on the appropriate advance care planning documents for each state and territory.

The enclosed Advance Care Planning Information Pack includes:

1. Relevant state and territory advance care planning documents and fact sheets*.
2. Fact sheet, *What Matters to Me: Conversation Guide.*
3. Fact sheet, *What do you want for your end of life care*?

We believe it is a basic human right to have your values, beliefs and preferences respected by family, carers and medical professionals if you can no longer express your wishes, so we encourage you to consider this information carefully. If you have any questions about advance care planning, please don't hesitate to contact your Care Manager.

Yours sincerely

Nia Briguglio
EGM – Aged Care Centres

**Please note for NSW residents who do not have capacity to express their own preferences, IRT recommends the use of the Queensland Health Statement of Choices document. This is because there is no statewide Statement of Choices document available in NSW.*

Level 3, 77 Market Street
Wollongong NSW 2500
T 134 478
E customerservice@irt.org.au
irt.org.au
ABN 52 000 726 536

Cardio Pulmonary Resuscitation (CPR)

Information for residents, customers, representatives and family

IRT's position on Cardio Pulmonary Resuscitation (CPR)

IRT understands it has a duty of care to its residents and customers, while also recognising that death is inevitable and a natural part of life. Our approach to life-prolonging measures such as CPR is guided by these two principles.

IRT has taken the position that our employees will not perform CPR on all residents/customers who are found unresponsive and not breathing normally (i.e. residents/customers who have suffered cardiac arrest).

However, in some emergency situations designated employees working in our aged care centres or providing home care services may perform CPR. An ambulance will always be called if CPR has been commenced.

When CPR will not be performed

Our employees will not perform CPR in the following circumstances:

- The resident/customer has a palliative approach in place, nearing the end of their life. (see *CPR in an emergency situation*, for residents with Advanced Care Planning documents)
- The resident/customer has expressly communicated their wish not to be resuscitated under any circumstances, via an Advance Care Directive or Statement of Choices.
- The cardiac arrest does not appear to be the result of an emergency situation.

CPR in an emergency situation

Employees who are trained in CPR are supported to perform CPR in the following circumstances:

- The cardiac arrest appears to be the result of an emergency - such as an accident, fall, choking event or medical episode - as distinct from a natural ending of life.
- The cardiac arrest does not appear to be the result of an emergency but the employee knows the resident/customer has expressly communicated their wish for CPR to be performed in all cases, via an Advance Care Directive or Statement of Choices.

IRT aged care centres and home care employees do not have access to Automatic External Defibrillators. If CPR is commenced an ambulance will always be called and defibrillation will only be performed by ambulance officers.

Advance care planning

IRT supports all residents/customers to be given the opportunity to complete an Advance Care Directive (ACD). A Statement of Choices (SoC) can be completed by the resident/customer's substitute decision-maker where the resident/customer does not have capacity to make decisions relating to their advance care planning.

ACD is a legally enforceable document, whilst a SoC helps guide decision making at a future time when the resident is unable to communicate their own wishes. SoC is not a legally enforceable document.

HEALTH DIRECTION

Medical Treatment (Health Directions) Act 2006

IMPORTANT NOTICE:

- *If this direction is inconsistent with an enduring power of attorney for a health care matter or a medical research matter that you have previously given, your attorney must comply with this direction.*
- *If this direction is inconsistent with an enduring power of attorney for health care matters or medical research matters that you make in the future, your attorney must comply with your enduring power of attorney.*
- *You can revoke this direction by clearly expressing to a health professional or someone else a decision to revoke the direction, or by making another direction.*
- *Subject to the above, the power to make decisions relating to the withholding or withdrawal of medical treatment to you, including treatment involving medical research, will now be exercised according to your instructions on this form.*

1. DIRECTION

I,

Person making the direction	*[name]*
	[address]

make this direction to refuse, or require the withdrawal of, medical treatment generally or a particular kind of medical treatment:

.....

.....

.....

.....

.....

.....

.....

.....

2. PREVIOUS DIRECTION REVOKED

I revoke all directions previously made by me under the *Medical Treatment Act 1994* (if any) and all other directions made by me under the *Medical Treatment (Health Directions) Act 2006* (if any).

3. CERTIFICATION

I certify that:

(i) I am an adult;

(ii) I do not have a guardian appointed or have impaired decision-making capacity; and

(iii) this direction is made voluntarily and without inducement or compulsion.

Signature of person making direction	
Date	

OR

I directed the following person to sign this direction on my behalf –

(Another person can sign the direction on your behalf in your presence if you are unable to sign it yourself.)

Name and address of person signing by direction	*[name]* *[address]*
Signature of person signing by direction	
Date	

(It is recommended that you or the person you have directed also sign at the foot of the first page.)

4. WITNESSES

(The witnesses must sign in the presence of each other and the person making the direction.)

Signature of witness 1	
Name	
Address	
Date	

Signature of witness 2	
Name	
Address	
Date	

* 1 5 3 0 5 *

ACT Health

Advance Care Plan Statement of Choices - Competent Person

Affix patient label or complete details

Name: _____

Address: _____

_____

DOB: _____ Telephone: _____

URN: _____(Hospital use only)

Name of Attorney(s) under Enduring Power of Attorney

1. Name:_____

Telephone number(s) of Attorney:

_____ (Home)

_____ (Mobile)

_____ (Work)

Relationship: _____

2. Name:_____

Telephone number(s) of Attorney:

_____ (Home)

_____ (Mobile)

_____ (Work)

Relationship: _____

3. Name:_____

Telephone number(s) of Attorney:

_____ (Home)

_____ (Mobile)

_____ (Work)

Relationship: _____

4. Name:_____

Telephone number(s) of Attorney:

_____ (Home)

_____ (Mobile)

_____ (Work)

Relationship: _____

Date of the Enduring Power of Attorney (EPA): _____

The following documents have been completed and are attached:

Enduring Power of Attorney: ☐ Yes ☐ No

Health Direction under the Medical Treatment (Health Directions) Act 2006: ☐ Yes ☐ No

Registered on the Donate Life register: ☐ Yes ☐ No

For more information about organ and tissue donation contact Donate Life on 6244 5625

I give permission for this information to be shared with my health care team.

Signed: _____ Date: _____

Copies of your Advance Care Plan have been given to: e.g. Canberra and Calvary Public Hospital; GP; Attorney(s) or Guardian; Residential Aged Care Facility; private hospital/health facility *(complete as many lines as applicable)*

1. _____

2. _____

3. _____

4. _____

5. _____

6. _____

This Advance Care Plan will be used to guide future medical decisions ONLY when you lose the ability to make or communicate your medical treatment decisions yourself. The law requires that this statement of your wishes must be taken into account when determining your treatment.

I _____,
(Your name)

of _____,
(Your address)

am of sound mind, and I have read and understand the importance of this document. I have also had this document explained to me and had all my questions answered to my satisfaction. I request that my stated choices recorded below, are respected by my family, appointed attorney(s) and by my doctors. In addition I request that they respect my values and wishes as we have previously discussed.

I understand that it is most important to discuss my wishes with my Enduring Power of Attorney(s), family and doctors so that they are aware of them. I also understand that the doctors will only provide treatment that is medically appropriate.

Living well, or an acceptable recovery/reasonable outcome after illness or injury can mean:

(Example: To be able to communicate meaningfully with family/friends; not be completely bed bound; to not be dependent on others for personal hygiene; to be able to eat and drink naturally; to have some mobility)

*To me 'living well' or an acceptable recovery/reasonable outcome means (please write what is important to you):

_____

_____

_____

My Choices About Life Prolonging Treatments *Initial the box that you want and put a line through the boxes that you do not want.*

e.g. breathing machine (ventilator), kidney machine (dialysis), feeding tube (PEG tube or nasogastric tube), operation, intravenous antibiotics, blood transfusion.

☐ I **do** want life prolonging treatments if it is medically appropriate.

Or

☐ In circumstances like those set out below I **do not** want life prolonging treatments at all. If life-prolonging treatment is commenced contrary to my wishes I request that it be discontinued.

Circumstances in which I would not want life-prolonging treatments include:

_____

_____

To me life prolonging treatments mean:

_____

_____

Or

☐ I only want life prolonging treatments **if** the doctors expect an acceptable recovery/reasonable outcome as described above.*

Or

☐ I wish to leave the decisions on life prolonging treatments to my Enduring Power of Attorney (if appointed) or my person in consultation with my doctors.

My choices about treatment if my heart stops or there are no signs of life (not moving, unresponsive, not breathing, unconscious).

CPR (Cardiopulmonary Resuscitation) can be attempted to restart a heart.

CPR (Cardiopulmonary Resuscitation) ***Initial the box that you want, put a line through the boxes that you do not want.***

☐ I **do** want CPR if it is medically appropriate

Or

☐ I **do not** want CPR at all

Or

☐ I **only want** CPR **if** the doctors expect an acceptable recovery/reasonable outcome as described above.*

ACT Health

Advance Care Plan Statement of Choices - Competent Person

Affix patient label or complete details

Name: _____

Address: _____

_____

DOB: _____ Telephone: _____

URN: _____(Hospital use only)

If your choices on the previous page relate to a current medical condition you can complete a Health Direction under the Medical Treatment Act 2006. You can talk to your Respecting Patient Choices Facilitator or doctor about this

(Complete if applicable)

My current medical condition (include any chronic condition or life limiting illness) _____

_____

_____

I wish to make the following further requests regarding my treatment for the conditions described above:_____

_____

_____

_____

Other points that are important to me

I ask that my Enduring Power of Attorney(s) include the following people in my health care decisions if there is time:

_____

_____

_____

_____

If I am nearing my death, I want the following (list things that would be important to you, e.g. care of a pet, religious or spiritual rituals, cultural customs):

_____

_____

_____

_____

If I am nearing my death and cannot speak, please give my family and friends the following message:

_____

_____

_____

_____

If there is not enough room to write all your requests and wishes, please attach further pages as necessary. All additional pages need to be signed, dated and witnessed.

I _____ hereby declare that the information completed above is a true record of my wishes on this date.

Signature _____ Date _____

(your signature or Mark)

Witness signature _____ Date _____

Witness name _____ **Relationship** _____

Respecting Patient Choices® Advance Care Planning

Frequently Asked Questions

What is Advance Care Planning?

Advance care planning (ACP) is a series of steps you can take to help you plan for your future health care. This program is about the promotion of autonomy and dignity.

You have the right to make decisions about your health care, now and for the future. Medical treatment should only be given with your fully informed consent and you have the right to refuse treatment.

If, in the future, you become unable to express your choices for treatment, your doctors and family/friends may not know what you would want. ACP gives you the opportunity to record, ahead of time, your choices in an Advance Care Plan.

There are three ways to record your healthcare choices:

1. Enduring Power of Attorney (legal document)
2. Statement of Choices (record of wishes and values regarding future medical treatments – non legal document)
3. Health Direction under the Medical Treatment (Health Directions) Act 2006 (legal document)

An ACP *ONLY* comes into effect if you lose legal capacity to make decisions about your medical treatment.

Why is it important?

Often, families are unaware of their loved one's views about what they would want done when too ill to speak for themselves. Families often feel burdened by the concern that they will make a wrong choice.

If there is not a clear statement of a person's wishes, doctors must treat them in the most appropriate way. This can mean aggressive treatments that the person might not have wanted.

Many people are now kept alive under circumstances that are not dignified and this can cause unnecessary suffering.

Where do I register them?

It is important that you send your Advance Care Plan documents to the ACT Health Respecting Patient Choices® (RPC) ACP Program, PO Box 11, WODEN ACT 2606. They will be scanned and placed on your electronic medical record at the Canberra Hospital.

Who can help me complete them?

Trained RPC ACP facilitators can assist you with completing the documents or introducing the subject with your family.

Please contact the Program if you would like to speak with a trained facilitator.

Need further information?

If you need assistance or would like more information please contact the Respecting Patient Choices Program, Health*CARE* Improvement Unit, 6244 3344 or rpc@act.gov.au.

Advance Care Planning Australia

BE OPEN | BE READY | BE HEARD

FACTSHEET FOR INDIVIDUALS

What is advance care planning?

If you were very unwell, and not able to communicate your preferences for care to others, who would you want to speak for you? And more importantly, what healthcare decisions would you want them to make?

Advanced illness or serious injury can sometimes mean that people cannot make their own decisions about health and personal care. This can happen to people of all ages, and especially towards end of life.

Writing an Advance Care Directive (values and/or instructional) lets you say what you would want, if you are ever unable to communicate for yourself.

Benefits for you and the people who care for you

Advance care planning:

- helps to ensure that a person's preferences, beliefs and values about health care are known and respected if they are too unwell to speak for themselves
- benefits those who are close to them. Research has shown that families of people who have done advance care planning have less anxiety and stress when asked to make important healthcare decisions for other people.

Making healthcare decisions for others can be difficult. An Advance Care Directive can give peace of mind and comfort as preferences are clear, understood and respected.

When should you make an Advance Care Directive?

You should start planning when you're healthy – before there's actually an urgent need for a plan. But having an Advance Care Directive in place becomes particularly significant towards the end of a person's life. About 85% of people die after chronic illness, not as the result of a sudden event – so it's important that your Advance Care Directive is ready in case it's required someday.

What do you need to do?

Be open

- Think and talk about your values, beliefs and preferences for current and future health care.
- Decide who you would like to speak for you if you become very sick and are not able to speak for yourself. Ask them if they are prepared to be your substitute decision-maker.

Ideally, they need to be:

- available (ideally live in the same city or region)
- over the age of 18
- prepared to advocate clearly and make decisions on your behalf when talking to your doctors, other health professionals and family members.

Depending on your state/territory, you may be able to appoint more than one substitute decision-maker.

Be ready

- Talk about your values, beliefs and preferences with your substitute decision-maker and other people involved in your care, such as family, friends, carers and doctors.
- Write your plan and/or appoint your substitute decision-maker. See advancecareplanning.org.au for the relevant form or advance care planning legal factsheet. Your GP or other health professionals can help support you to document your choices.

There are different legal requirements in different Australian states and territories, so it is a good idea to ask for help. In some states and territories there are important rules regarding who can witness documents for you. See your relevant advance care planning legal factsheet.

Advance Care Planning Australia is supported by funding from the Australian Government.

Austin Health

Advance Care Planning Australia

BE OPEN | BE READY | BE HEARD

FACTSHEET FOR INDIVIDUALS

Be heard

- A written Advance Care Directive will make things easier for your substitute decision-maker(s), if the need ever arises. It will give everyone peace of mind, knowing your preferences are heard and respected.

Make copies and store them with:

- your substitute decision-maker(s)
- your GP/local doctor
- your specialist(s)
- your residential aged care home
- your hospital
- myagedcare.gov.au.

You don't have to give a copy to each of the above, but make sure your substitute decision-maker and main doctor each has a copy.

- Load your Advance Care Directive into your 'My Health Record' at myhealthrecord.gov.au
- Review your Advance Care Directive regularly – for instance each year. You should review it if there is a change in your health, personal or living situation.
- Give your substitute decision-maker and doctors an updated copy of your Advance Care Directive if you make changes and keep it safe.

The law and advance care planning

Different states and territories in Australia have different laws on advance care planning. When planning for your own future care, it will be helpful to understand the law in your own state/territory. See advancecareplanning.org.au for information.

Depending on the state/territory:

- A substitute decision-maker may be legally appointed as an Attorney, Enduring Guardian, Decision-Maker or Medical Treatment Decision-Maker.
- An Advance Care Directive may also be called an Advance Health Directive, Health Direction or Advance Personal Plan.

Conversation starters

To get started, choose a quiet setting where you have a lot of time, so you know that you won't be interrupted. Be patient and take your time: you and your loved ones might need a few moments to think.

Sometimes you might get a bit sidetracked and that's okay. Let the conversation happen naturally. You don't need to talk about everything all at once. Remember that advance care planning is an ongoing conversation.

Starting the conversation can be the hardest part, so here are a few ways to begin:

- I was thinking about what happened to … and it made me realise that …
- I would want … to make medical decisions on my behalf if I was unable to.
- Being able to … is the most important thing to me.
- If … happened to me, I would want …

Where can I get more information?

Advance Care Planning Australia

advancecareplanning.org.au

National Advisory Service: 1300 208 582

learning.advancecareplanning.org.au

Advance Care Planning Australia is supported by funding from the Australian Government.

Austin Health

ACT **Health**

Affix patient label or complete details

Name: _____

Address: _____

_____ Phone: _____

DOB: _____ Sex: _____

URN: _____ (Hospital use only)

ADVANCE CARE PLAN STATEMENT OF CHOICES - NO LEGAL CAPACITY

Attorney under Enduring Power of Attorney/Guardian ***(please circle to identify which role)***

1. Name: _____

Telephone number(s) of Attorney:

_____ (Home)

_____ (Mobile)

_____ (Work)

Relationship: _____

2. Name: _____

Telephone number(s) of Attorney:

_____ (Home)

_____ (Mobile)

_____ (Work)

Relationship: _____

3. Name: _____

Telephone number(s) of Attorney:

_____ (Home)

_____ (Mobile)

_____ (Work)

Relationship: _____

4. Name: _____

Telephone number(s) of Attorney:

_____ (Home)

_____ (Mobile)

_____ (Work)

Relationship: _____

Date of the Enduring Power of Attorney (EPA): _____

The following documents have been completed and are attached:

Enduring Power of Attorney or Guardianship Orders (as applicable): ☐ Yes ☐ No

Health Direction under Medical Treatment (Health Directions) Act 2006: ☐ Yes ☐ No

Registered on the Australian Organ Donor Register ☐ Yes ☐ No

For more information about organ and tissue donation contact Donate Life on 6174 5625

I give permission for this information to be shared with the health care team.

Signed: _____ Date: _____

Copies of your Advance Care Plan have been given to: e.g. Canberra and Calvary Public Hospital; GP; Attorney(s) or Guardian; Residential Aged Care Facility; private hospital/health facility *(complete as many lines as applicable)*

1. _____

2. _____

3. _____

4. _____

5. _____

6. _____

DO NOT WRITE IN THIS BINDING MARGIN

ADVANCE CARE PLAN STATEMENT OF CHOICES - NO LEGAL CAPACITY

15306

15306(0518)

This document relates to the following person: _____

I understand that he/she has been assessed as not having legal capacity.

I have made choices based on the best interests of the person taking into account their wishes, the wishes of family members and significant others, and the benefits and burdens of treatment. I request that the stated choices recorded below are respected by health professionals now, and in the future.

Please note: The law requires that this statement be taken into account when determining treatment for this person.

1. Life Prolonging Treatments

Initial *the boxes you want and cross out the boxes you don't want.* You may write specific requests on the lines provided.

☐ **1.** I would like life prolonging treatments to be commenced and continued, including Cardio Pulmonary Resuscitation (CPR), while they are medically appropriate and remain in his/her best interests.

You may write specific requests here: _____

_____

_____

_____

Or

☐ **2.** If he/she is acutely ill, unable to communicate responsively with family and friends, and it is reasonably certain that he/she will not recover, I want him/her to be allowed to die naturally and be cared for with dignity. I do not want him/her to be kept alive by extraordinary or overly burdensome treatments that might be used to prolong his/her life (e.g. Cardio Pulmonary Resuscitation [CPR]). If any of these treatments have been started, I request that they be discontinued. However, I do want Palliative Care that includes medications and other treatments to alleviate suffering and keep him/her comfortable, and to be offered something to eat and drink.

You may write here specific treatment(s) that you want or don't want: _____

_____

_____

_____

_____

_____

2. Other requests with regard to medical care

e.g. Such as circumstances in which he/she does or does not want a particular treatment.

_____

_____

_____

_____

_____

_____

_____

_____

_____

_____

_____

_____

DO NOT WRITE IN THIS BINDING MARGIN

15306(0518)

ACT **Health**

Affix patient label or complete details

Name: _____

Address: _____

_____ Phone: _____

DOB: _____ Sex: _____

URN: _____ (Hospital use only)

ADVANCE CARE PLAN STATEMENT OF CHOICES - NO LEGAL CAPACITY

3. Other points that are important to the person

If the person had other end of life wishes, e.g. organ or body donation, you may wish to attach documentation to this plan. Please note: it is the next-of-kin/family that consent to organ donation.

I ask that doctors include the following persons in their health care decisions if there is time:

_____

_____

_____

_____

_____

_____

_____

If the person is nearing death, I want the following (list things that would be important to them, e.g. care of a pet, religious or spiritual rituals, cultural customs):

_____

_____

_____

_____

_____

_____

Signed by: _____ Date: _____

Attorney / Guardian (Please circle your relationship with the subject)

Other persons present at discussion and formulation of this plan:

Name	**Relationship**
_____	_____
_____	_____
_____	_____
_____	_____
_____	_____
_____	_____

Doctor's Review of the plan **Date:** _____

Doctor's name: _____

Doctor's signature: _____

DO NOT WRITE IN THIS BINDING MARGIN

15306(0518)

Frequently Asked Questions

What is Advance Care Planning?

Advance care planning (ACP) is a series of steps you can take to help you plan for your future health care. ACP is based on the principles of autonomy and dignity.

You have the right to make decisions about your health care, now and for the future. Medical treatment should only be given with your fully informed consent and you have the right to refuse treatment.

If, in the future, you become unable to express your choices for treatment, your doctors and family/friends may not know what you would want. ACP gives you the opportunity to think about, discuss and record, ahead of time, your choices.

An ACP *ONLY* comes into effect if you lose legal capacity to make decisions and express, in some way, your wishes and choices about your medical treatment.

Why is it important?

Up to 50% of Australians will not be able to make or express their own decisions when they are near death. Doctors and family members will be unaware of any treatment preferences at this time if these have not been discussed and recorded earlier.

Often, families are unaware of their loved one's views about what they would want done when too ill to speak for themselves. Families often feel burdened by the concern that they will make a wrong choice.

If there is not a clear statement of a person's wishes, doctors must treat them in the most appropriate way. This can mean aggressive treatments that the person might not have wanted.

What documents do I need?

The three ways you can record your choices these include:

1. **Enduring Power of Attorney** (EPA) - a legal document appointing a substitute decision maker of your choice.
2. **Advance Care Plan-Statement of Choices** (ACP) a guiding document outlining your wishes and preferences for future health care.
3. **Health Direction** a legal document with clear direction about refusal or withdrawal of treatment

Where do I register them?

It is important that you send **copies** all your documents to the ACT Health Advance Care Planning (ACP) Program. They will be scanned and placed on your electronic medical record at the Canberra Hospital and also Calvary Public Hospital. You may also like to give a copy to your GP and your attorneys (nominated substitute decision makers).

Need further information?

If you need assistance or would like more information please contact the Advance Care Planning Program, Clinical Quality and Safety Unit, 6205 3178 or email acp@act.gov.au.

Advance Care Planning Australia

BE OPEN | BE READY | BE HEARD

FACTSHEET FOR SUBSTITUTE DECISION-MAKERS

What is advance care planning?

If you knew someone who became very unwell and was not able to communicate their preferences to others, would you know what they wanted? Could you make healthcare decisions on their behalf?

If your loved one became more unwell or had a sudden emergency they may no longer be able to make their own decisions about health and personal care. This can happen to people of all ages, and especially towards end of life.

Writing an Advance Care Directive lets a person say what they would want, if they are ever unable to communicate for themselves.

Benefits for you and the people you care for

Advance care planning:

- Helps to ensure that a person's preferences, beliefs and values about health care are known and respected if they are too unwell to speak for themselves
- Research has shown that families of people who have done advance care planning have less anxiety and stress when asked to make important healthcare decisions for other people.

What does a substitute decision-maker do?

When a person prepares their Advance Care Directive, they may invite someone to be their substitute decision-maker. If the person loses their ability to make their own healthcare decisions, the substitute-decision maker can then make decisions on their behalf. The Advance Care Directive will provide direction and guidance.

Some state/territory laws may allow for more than one substitute decision-maker to be appointed.

How can a substitute decision-maker help with advance care planning?

Be open

- If someone asks you to be their substitute decision-maker, think about what it might mean for you before you agree.

Ideally, you need to be:

- Available (live in the same city or region) or readily contactable
- Over the age of 18
- Prepared to advocate and make decisions clearly and confidently on the person's behalf when talking to doctors, other health professionals and family members if needed
- Comfortable with encouraging the person to talk through their preferences with their family members and close friends.

Be ready

- Talk with the person about their values, beliefs and life goals. Make sure you understand and respect their approach to health care, living well and end-of- life decisions.
- If you and the person have conflicting beliefs, be honest with them. Remember that you may be called upon to advocate for them. If your beliefs are too different, it may be better for them to choose someone else.
- Talk about any potential issues that may arise with family members or partners who have different views. How will you cope with any disagreement that could arise? Do they know you are a substitute decision-maker?
- If you agree to being a substitute decision-maker, discuss whether they want you to be legally appointed.

Be heard

- Encourage the person to write an Advance Care Directive.
- Ask for a copy of the Advance Care Directive and keep it safe. Familiarise yourself with the person's preferences and ask them to explain anything that isn't clear.
- Encourage them to review their Advance Care Directive every year or if there is a change in their health or personal situation.
- Encourage them to load their Advance Care Directive onto 'My Health Record' at myhealthrecord.gov.au

Advance Care Planning Australia

BE OPEN | BE READY | BE HEARD

FACTSHEET FOR SUBSTITUTE DECISION-MAKERS

What others say about being a substitute decision-maker

"I did what needed to be done to make her quality-of-life the best it could possibly be under the circumstances."

"I've read Dad's plan. It is so valuable to know because it's not a plan I would have ever developed myself."

"I was hoping that the decision I made was the same decision that the person I was acting on behalf of would have made."

The law and advance care planning

When you are appointed as a substitute decision-maker, it will be helpful to understand the law in your state/territory. Different states and territories in Australia have different laws regarding advance care planning. There are also common law decisions in advance care planning.

Depending on the state/territory:

- A substitute decision-maker may be legally appointed as an Attorney, Enduring Guardian, Decision-Maker or Medical Treatment Decision-Maker.
- An Advance Care Directive may also be called an Advance Health Directive, Health Direction or Advance Personal Plan.

Conversation starters

To get started, choose a quiet setting where you have a lot of time, so you know that you won't be interrupted. Be patient and take your time: you and your loved ones might need a few moments to think.

Sometimes you might get a bit sidetracked and that's okay. Let the conversation happen naturally. You don't need to talk about everything all at once. Remember that advance care planning is an ongoing conversation.

Here are some questions you may like to ask them:

- What do you currently value about your life?
- If your current health condition (e.g. cancer, dementia) got worse, what kind of medical treatment would you want and do not want?
- Describe a good day for you.
- If there was an emergency what kind of medical treatment would you want or not want?

At times, it can be challenging

Making medical decisions on behalf of someone else can be challenging.

When making decisions for someone else, you may:

- Feel uncertain about the outcomes of some decisions
- Feel that the preferences of the person for whom you are making decisions are unclear
- Question whether the decision you are making is the right one
- Have values and preferences that are in conflict with those of the person for whom you are making decisions
- Disagree with family members and/or treating health professionals over certain decisions.

Questions to ask your loved ones's doctor:

- What are the risks and likely outcomes of this treatment or procedure?
- Are there other safer options available?
- What are the financial costs of this treatment or procedure?

Self-care is important

While being a substitute decision-maker is an important role, looking after yourself is also important. If you feel overwhelmed about being a substitute decision-maker we recommend that you seek counselling and support. You can also access your religious or spiritual communities and other social networks to help you through this process.

Knowing your rights

If you feel you are not the right person or you can no longer fulfil your duties, you can resign from your appointment. Be sure to inform the person who appointed you as their substitute decision-maker so they can appoint someone more suitable for the role.

We're here to help

Free information is available from:

Advance Care Planning Australia

advancecareplanning.org.au

National Advisory Service: 1300 208 582

learning.advancecareplanning.org.au

Advance Care Planning Australia is supported by funding from the Australian Government.

Austin HEALTH

What Matters to Me:

Conversation Guide

MY END OF LIFE CARE

Talking about what matters to me

Talking to loved ones about

Your End-Of-Life Care

1

Getting started

Talking about end-of-life care is different for everyone—some people find it overwhelming and confronting, others may be more accepting. Be prepared to give it some time and, if necessary, have a number of conversations to make your wishes fully known and understood.

- Try and find a quiet space where you can speak openly and calmly.
- Think about who you would like in the room. Is it your spouse or partner? Your child, sibling, or good friend?
- Remember that you can share as much or as little information as you would like.

2

Talking about 'why'

Your loved ones may be wondering why you want to talk about end-of-life care. They may not know much about Palliative Care or Advance Care Planning.

- You could try explaining to them that, if you were to become unexpectedly sick, you don't want them to have to make stressful decisions on your behalf.
- Remind them that this information will help them in a time of stress when emotions can run high.
- Gently communicate that it's important that your end-of-life care happens the way you want it to.

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Conversation starters

Sometimes, the hardest part about difficult conversations can be knowing where to start. You could try some of the below openers to help you get started.

- "I know it might be hard to talk about, but it's really important to me."
- "We've talked a bit about what happens after I pass away, but we haven't spoken about my end-of-life care."
- "I've been speaking to my doctor, and they have asked me to think about a few things..."

4

Talking about your 'wishes'

An important part of this conversation is communicating your wishes clearly. Remember that there are no right or wrong answers—end-of-life care is very personal. If you haven't considered your end-of-life care before, the Palliative Care Australia website has useful resources that may help you. (www.palliativecare.org.au)

- "If I was no longer able to make decisions about my treatment or care, I would like this person to be my substitute decision-maker..."
- "When the end of my life approaches, I would like to be cared for at this location..."
- "This is the type of health care I would like to receive..."

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Next steps

It is a good idea to end the conversation with some next steps. If you haven't already, you could start to formalise your wishes in the form of an Advance Care Plan (also known as an Advance Health Directive in some states).

This may involve making an appointment with a health professional including your GP.

Visit www.health.gov.au/palliativecare

MY END OF LIFE CARE

Talking about what matters to me

Australian Government

Department of Health

What do you want for your end of life care?

Australian Government
Department of Health

MY END OF LIFE CARE
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It's normal not to want to talk about "it", that is "death or dying".

82% of Australians feel that talking about their death and dying wishes is important but when it comes down to it, most people don't actually bring themselves to have the conversation. In fact, almost half of us (43%), fall into the 'out of sight out of mind' way of thinking.

Why don't we want to talk about it?

While it's becoming more normal as we grow older to ponder our funeral plans or make a will so as to not burden loved ones, our approach to our end of life care is still very much taboo as a conversation topic.

Common reasons for this are:

- Not thinking it is necessary—because we're too healthy or too young
- Not knowing how to start the conversation
- Not wanting to upset loved ones by talking about death or dying
- Not understanding what's involved in palliative care versus end of life care and what steps you need to take to make a future plan.

Why talk about end of life care?

While talking about end of life care isn't easy, there are good reasons to start the conversation early:

- It helps empower you to take control about your end of life care and dying wishes ahead of time and in line with the things you value most
- It helps take the burden off loved ones trying to understand your desires and wishes.

Palliative Care is commonly mistaken as the medical care provided only when death or dying is imminent. Understandably, this misconception alienates many of us from having this important conversation much earlier in our lives.

What is palliative care?

Palliative care is about improving your quality of life when facing a life-limiting illness. It focuses on your individual needs and aims to prevent and relieve suffering by treating not only the physical, but also the emotional, social and spiritual symptoms.

Care may include:

- Relief of pain and other symptoms
- Resources such as medical equipment
- Assistance for families to come together to talk about sensitive issues
- Support for people to help meet cultural obligations
- Support for emotional, social and spiritual concerns
- Counselling and grief support.

What is end of life care?

End of life care is for people of any age and is about the palliative care services you and your family receive when you are facing your end of life.

It often involves many health professionals bringing together a range of skills to manage your illness. Wherever possible end of life care is provided where you and your family want care—at home, in hospital, in a hospice or a residential aged care facility.

Conversation starter.

So how do you talk about something nobody wants to talk about?

The ability to prompt discussions about end of life care will be easier for some of us. There are many factors at play—your mindset, values, beliefs, culture, health, family relationships and so on.

Some things to keep in mind:

- There is no right or wrong way to go about having a conversation—it's very personal to you, your family and friends
- The conversation doesn't have to be rushed—take time to first self reflect on what's important to you
- Conversations like this are likely to happen and be resolved over time—embrace suitable opportunities as they arise
- Resources and support services are available to help you make a start when you're ready.

Taking your wishes and turning them into a plan.

The next important step after having conversations with your family and health care professionals is to create a plan that documents your wishes. This is known as an **Advance Care Plan (ACP)** and is the process of planning your medical care in advance regardless of your age or health. It is particularly important if you have a chronic illness, a life-limiting illness, or are aged over 75 years.

It talks about your values, beliefs and preferences so your family and health care providers can guide decision making if you cannot make or communicate your decisions in the future.

An **Advance Care Directive (ACD)** is different from an Advance Care Plan—it records your preferences in a document that is recognised by common law or legislation. It is usually discussed with your doctor and ensures your decisions are informed by your health. An ACD ensures your treating doctor understands your wishes.

As part of your ACD you can choose someone you trust to make decisions on your behalf. This person is known as a substitute decision maker (SDM) and they can act as your voice, if you are no longer able to.

While end of life care planning can be overwhelming, having the conversation and documenting your wishes early will help to provide clarity and ease potential conflict with family and friends at a time when emotions run high.

For more information about having the conversation visit www.health.gov.au/palliativecare

Australian Government
Department of Health

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