# Advance care planning (ACP) in the ACT







### **Acknowledgment of Country**

We wish to acknowledge the Ngunnawal people as traditional custodians of the land we are meeting on and recognise any other people or families with connection to the lands of the ACT and region. We wish to acknowledge and respect their continuing culture and the contribution they make to the life of this city and this region. We would also like to acknowledge and welcome other Aboriginal and Torres Strait Islander people who may be attending today's event.

Aboriginal and Torres Strait Islander peoples should be advised that this document refers to material of a sensitive nature.

Adapted from Queensland Government (Queensland Health) Statement of Choices.

ACT Health is comitted to providing quality care to those who die in the ACT and extending this care to family and friends. We would like you to let us knows how well you felt our services supported you and what we could have done better. Please provide any feedback either to the service directly or at:

https://www.health.act.gov.au/services-and-programs/end-life-and-palliative-care



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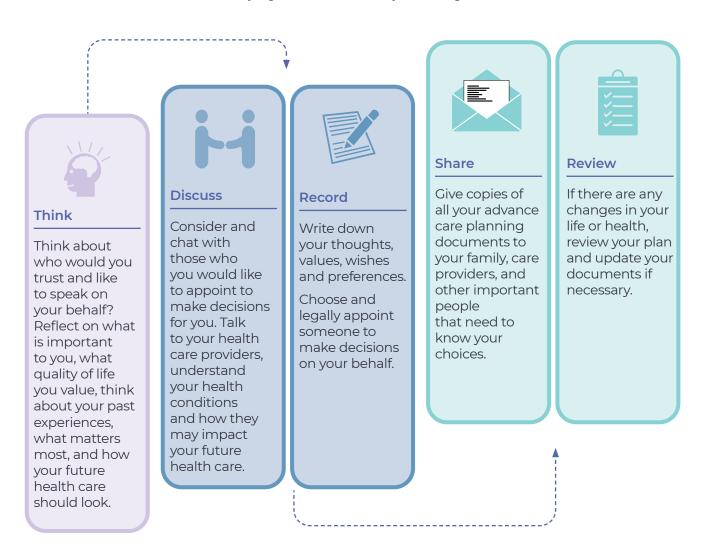
# Section One - Frequently Asked Questions

# 1. What is Advance care planning?

If your choices for future health care are known, they can be respected. Advance care planning (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 you become unable to express your choices for treatment in the future, your doctors and family/friends may not know what you would want. Advance care planning allows you to think about, discuss, and record your choices ahead of time.

#### ACP is a series of steps you can take to plan for your future healthcare



### Think now, plan soon, peace of mind when you need it

# 2. Why should I plan ahead?

Up to 50% of all Australians will not be able to make or express their own end of life decisions. Everyone should consider advance care planning, regardless of your age or health. Ideally, you should start planning when you're healthy - before there's actually an urgent need for a plan.

Advance care planning is particularly important for people who are older and are frail, or people who have a chronic illness, an early cognitive impairment

such as dementia, or are approaching their end of life. About 85% of people die after chronic illness, not as the result of a sudden event.

If you haven't documented your preferences or identified a substitute decision-maker, and you become seriously ill or injured, doctors will make treatment decisions based on their assessment of your best interests. This may include treatments that you may or may not want.

# 3. What documents are used in Advance care planning in the ACT?

1	Enduring Power of Attorney (EPOA)	Essential to have someone legally appointed to speak for you.	The EPOA is a legally binding document appointing your chosen decision maker/s with instructions on how they can act and what they can do. It can be completed independently with two authorised witnesses. (see "The Power to Choose" publication on the ACT Public Trustee and Guardian website). NSW residents appoint an Enduring Guardian for medical decision making – this is recognised in the ACT.
2	Statement of Choices	To think about, discuss and record your choices and guide those making decisions for you.	This outlines what matters most to you to live well. You can be specific about your choices for resuscitation and life prolonging or medical treatments and care that may be offered when you can no longer choose for yourself. This is recognised in common law.
3	Health Direction	An option to legally refuse or withdraw medical treatment.	You have the right to stop, or choose not to have, medical treatment now and in the future. A Health Direction is effective immediately. Not everyone has a Health Direction. You can complete one later if you feel you need to. It is best completed with your GP/doctor.

# 4. When is my Advance Care Planused?

Advance care planning is ONLY used if/ when you lose legal capacity to make decisions and express your wishes and choices about your medical treatment. It is a legal requirement that you are given the necessary support and information to participate in decisions that affect your life to the greatest extent practicable.

# 5. What is legal capacity?

The ability to make your own decisions is called capacity. You can make a decision if you can understand the situation at hand and the information given. Capacity includes weighing up the options and consequences and retaining and communicating this in some way.

The law presumes every adult has the capacity to make their own decisions about all aspects of their life (such as health, finance, and lifestyle), including who they choose to make decisions for them in the future (appointing an EPOA) and what health care decisions should be made if they were unable to voice these themselves.

# 6. If advance care planning documents are ONLY used when capacity is lost, how and when, is this decided?

Capacity may be temporarily lost during an acute illness or following an accident, or ongoing poor health and noticeable cognitive decline may be evident. A formal assessment of a person's capacity may be needed if there is concern that their ability to make their own decisions is affected.

A medical professional will usually assess decision-making capacity. Once assessed, the person may either be deemed to have capacity to make decisions, or not have it. If deemed to have capacity at that time, the person can continue to make decisions for themselves. If deemed not to have decision-making capacity, this is documented and the EPOA comes into effect. A substitute decision maker, usually the appointed EPOA, may then make decisions on the person's behalf. A Statement of Choices – no legal capacity format can be completed by the EPOA.

If an EPOA is not in place, the medical team may appoint a suitable person to act as emergency 'Health Attorney' to make urgent healthcare decisions. Ongoing health, financial, or lifestyle decisions may require an application to the Guardianship Tribunal to appoint a permanent Substitute Decision Maker called a Guardian.

# 7. What are lifeprolonging and medical treatments?

Sometimes after a long illness or acute injury, the body's organs and functions require support to work properly. Life prolonging treatments keep organs functioning, and the person may die without these treatments. They include but are not limited to breathing tubes and support (intubation and ventilation), resuscitation such as CPR (cardiopulmonary resuscitation), dialysis to support kidney function and nutritional support through tube feeding.

Medical treatments may be considered life-prolonging but are also helpful to keep a person comfortable. They include but are not limited to blood and blood product transfusion, intravenous therapy, surgery, oxygen, medicines to treat infections and imbalances. Medical interventions may also include investigations, observations and tests.

# 8. What should I know about Cardiopulmonary Resuscitation (CPR)?

CPR is an emergency treatment to attempt to restart a person's heart or breathing if it stops suddenly. The person may have chest compressions (to make the heart pump), a tube put into their lungs to help them breathe (intubation), or an electric shock to their chest (defibrillation). If this is successful, admission to intensive care usually follows.

It is important you have all the information you need before you decide if you want CPR attempted. The success of CPR depends on a person's overall medical condition and age. Please talk with your GP/doctor about this.

In an emergency, the decision to start CPR is urgent and may be commenced without your decision-makers being notified.

# 9. Can I change my documents?

Yes. Advance care planning documents should be reviewed and changed if your wishes and circumstances change. Most important are the ongoing conversations with those you have chosen to make decisions for you. It is also essential to understand your health conditions and how they can change over time and impact your future health care.

Advance care planning is not always about the end of life; it is a way to let others know how you want to live.

# 10. Can my family override my choices?

Your family needs to be aware of your treatment preferences so that they can respect and carry out your wishes. They will be making these decisions for you at a stressful time, and the Statement of Choices and the discussions you have had can guide and support them to do this.

# 11. How and where can I share my advance care planning documents?

Keep your originals safe. You can share your documents with whomever you wish. You can upload or give copies of your documents to:



Your family, chosen family, other important people, appointed Substitute Decision Maker(s)/Attorney(s).



#### **Canberra Health Services**

Mail your documents to Canberra Health Services Health Information Services PO Box 11 Woden ACT 2606 or email them to CHS.CPFScanning@act.gov.au



Your general practitioner, treating specialist or private hospital on admission.



**Care Providers** (example Residential Aged Care Facilities or home care)



MyDHR – you can upload all ACP documents so you have all your ACT public health information stored on the Digital Health Record Add an advanced care plan to MyDHR



My Health Record- you can upload all ACP documents to this nationally accessible record Add an advance care plan | My Health Record

#### The Public Trustee and Guardian

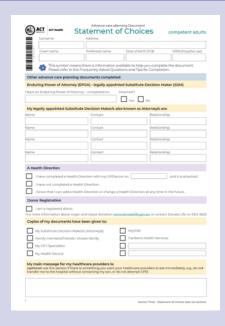
If you have prepared an Enduring Power of Attorney ('EPA') with the Public Trustee and Guardian ('PTG'), advanced care documents may also be stored at the PTG, by emailing them to the ptg@act.gov.au



# Section two - Tips for completing the Statement of Choices for competent adults

The Statement of Choices (SoC) is an important part of your advance care plan (ACP). The information here will only be used when you cannot make your own decisions or tell others what you want. By law, when someone else is making a health care decision for you, they must consider your choices. Use this form to record what is important to you and have discussions with those you have chosen to speak for you.

# Page one: Important information to identify you and your plan



- Use a black pen.
- Fill in your full name, address, and date of birth to correctly identify yourself on each page.
- The Unique Record Number or URN will be added by your health provider if necessary.
- Indicate if you have other documents in place as part of your advance care plan and attach them as necessary. Refer to Section one FAQs for an explanation of these documents.
- Add your chosen decision-makers and their best contact number and relationship to you e.g., partner, son, friend, chosen family.
- Tick the boxes or add additional information to indicate who you will share the document with.
- My main message: This section is helpful if there is important information you want your health care providers to see immediately. for example no CPR or do not transfer me to hospital without contacting my daughter.



# Page two: Your Values and wishes

Deciding the treatments that you would or would not want in the future is difficult. Advance care planning is a process that aims to focus on what matters most to you, defining quality of life and an acceptable recovery after illness or injury so that your decision-makers can make choices with this in mind.

Your Statement of Choices will be your voice when your decision makers are acting for you.

# Examples of other people's words about what matters most

It helps to reflect on what matters most, what living well means to you. What you value and enjoy, along with your past experiences, best hopes, and worst fears for your future health and what might be unacceptable.



"To stay active and independent for as long as I can."

"To communicate my needs and interest to others."

"To be involved in deciding my care."

"To be able to eat and drink naturally."

"Not to be dependent on machines."

"I value being around family and friends, participating and engaging with my community, caring for my family, to be able to have a laugh, to feel comfortable and safe."

"I enjoy walking, reading, watching TV and old movies, time in the garden, being social, puzzles, crosswords, listening to music and keeping up with current affairs."

"It would be unbearable for me if I were dependent on others for care and mobility, and I could no longer communicate or eat and drink."

"I want my kids to know I trust their ability to decide for me, and while this may be hard, I want them to support each other, not argue, choose as I would have done, use quality and comfort to guide you - it's OK."

# What else might be important?

You can note relevant medical or physical conditions and specific personal or treatment needs that are important to you. For example:

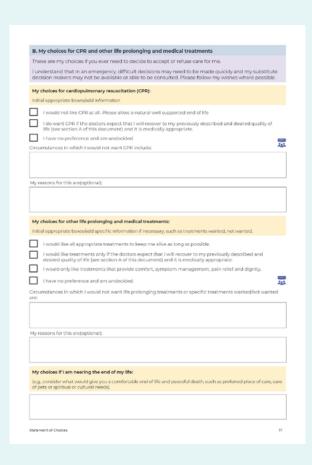
"Lying on my left side is painful."

"I am hearing impaired; speak clearly and directly to me. "

"Keep/stop regular medications, unless...."

# Page three:

# Your choices for CPR and other life prolonging and medical treatments



You can write down your choices for Cardiopulmonary Resuscitation (CPR) and other life-prolonging and medical treatments. This decision may need further discussion with your doctor and careful consideration regarding your age and current medical condition. Allowing a natural death acknowledges the dying process and hope for a peaceful, well-supported end of life; it ensures only comfort measures are provided. You can add further information about what would be important to you at the end of your life, such as preferred place to be or important cultural or spiritual needs.

## Page three:

# Choices for life prolonging treatments. Other people's words:



"I do not want CPR in light of my advanced age and ongoing health concerns; I would prefer a natural death with family around me and any pain and symptoms managed well."

"If life-prolonging treatments have started against my wishes, please stop them. Continue to give me appropriate medical treatments to make me comfortable and allow a natural well-supported end of life."

"If I am at the end stage of an illness and all treatments have been exhausted or I have any impairment leading to ongoing complete physical dependence and inability to make my own decisions and communicate. (e.g. advanced dementia, a major stroke or organ failure, injury or accident with brain injury and a prolonged period of unconsciousness). I do not want any life-prolonging or medical interventions unless it provides immediate comfort or time to see my family. Please provide me with a well-supported, dignified end of life. "

"Don't keep me going if I am not responding".

"I only accept these treatments if the likely result will allow me to have the quality of life and capabilities I have described in my values and wishes."

# End of life preferences. Other people's words:



"I am hoping for a natural, peaceful, dignified, and well-supported end of life, family close and to be cared for in my preferred or best place, pets close by and cared for after my death."

"Important religious, spiritual or cultural customs provided (specify)."

"I would prefer to be cared for at home, if possible, but accept hospice or hospital care if necessary."

# Page four:

# Witnessing and sharing your plan



- Read through and acknowledge the declaration of understanding. Anyone over the age of 18 can sign and witness your Statement of Choices.
- It is a good idea to review your documents from time to time, especially if your health or personal circumstances change. You can either note that there are no changes or complete a new one.
- Keep your original document safe, give copies to your family/substitute decision-makers/attorney/s along with other advance care planning documents (Enduring Power of Attorney and Health Direction). Share a copy of each with the places you have nominated.
- You can add all advance care planning documents to the national My Health Record.

You can talk with your doctor about your choices for current and potential health conditions and concerns. The Advance Care Planning Program at Canberra Health Services can help you complete your forms.

Call this free service on (02) 5124 9274 or

Email: acp@act.gov.au for advice or to make an appointment.

#### There is more information available:

- » Enduring Power of Attorney on the ACT Public Trustee and Guardian's website <a href="https://www.ptg.act.gov.au">https://www.ptg.act.gov.au</a> 'The Power to Choose' and 'My Right to Decide'
- » Advance care planning Australia <a href="https://:www.advancecareplanning.org.au">https://:www.advancecareplanning.org.au</a>
- » My Health Record <u>https://www.myhealthrecord.gov.au</u>
- » ACT Health /Canberra Health Services <a href="https://www.health.act.gov.au/services/advance-care-planning">https://www.health.act.gov.au/services/advance-care-planning</a>







# Advance care planning Document Statement of Choices competent adults

	Surname:	Address			
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* 1 5 3 0 5 *	Given name	Preferred name	Date of birth [	OOB	MRN:(hospital use)
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Other	advance care planning do	cuments complete	d:		
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I have a	n Enduring Power of Attorney	- completed on:	Attached?		
			Yes N	0	
My le	gally appointed Substitute	Decision Maker/s al	lso known as Atto	orney/s are:	
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	amily members/friends / chos	en family	Canberra He	alth Services	
N	1y GP / Specialists				
	Ny Health Record				
My m	ain message for my health	care providers is:			
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A. N	My va	lues and	d wishes -	What	matters	most.
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These are my values and wishes that I want considered if my chosen decision makers are required to make health care decisions for me. They know how I want to live, and how I would like to be treated. This Statement of Choices is my voice. Please respect and consider my wishes.

I ask all family members and healthcare professionals involved in my care to do the same.
My desired quality of life and acceptable recovery after illness or injury (living well):
(e.g., Think about your past experiences, best hopes, worst fears. What matters to you, how you would like to live, what you value, enjoy and what gives your life meaning and quality; what circumstances might be unacceptable).
My understanding of my current health conditions:
(e.g., include any chronic or life limiting illness or health concerns. You can add personal and medical matters that you need to be managed or considered, i.e., medications required, hearing impairment, or assistance and care needs).
<b>30</b>
More important information:
(e.g., include the following people in my health care decisions if there is time. Any religious, spiritual, or cultural needs that are important to you. A message, or things you want your family to know).



### B. My choices for CPR and other life prolonging and medical treatments

These are my choices if you ever need to decide to accept or refuse care for me.

I understand that in an emergency, difficult decisions may need to be made quickly and my substitute decision makers may not be available or able to be consulted. Please follow my wishes where possible.

My choices for cardiopulmonary resuscitation (CPR):
Initial appropriate boxes/add information
I would not like CPR at all. Please allow a natural well supported end of life.
I do want CPR if the doctors expect that I will recover to my previously described and desired quality of life (see section A of this document) and it is medically appropriate.
I have no preference and am undecided.
Circumstances in which I would not want CPR include:
My reasons for this are(optional):
My choices for other life prolonging and medical treatments:
Initial appropriate boxes/add specific information if necessary, such as treatments wanted, not wanted.
I would like all appropriate treatments to keep me alive as long as possible.
I would like treatments only if the doctors expect that I will recover to my previously described and desired quality of life (see section A of this document) and it is medically appropriate.
I would only like treatments that provide comfort, symptom management, pain relief and dignity.
I have no preference and am undecided.
Circumstances in which I would not want life prolonging treatments or specific treatments wanted/not wanted are:
Circumstances in which I would not want life prolonging treatments of specific treatments wanted/not wanted are.
My reasons for this are(optional):
My choices if I am nearing the end of my life:
(e.g., consider what would give you a comfortable end of life and peaceful death, such as preferred place of care, care of pets or spiritual or cultural needs).

### My declaration of understanding and witnessed signature. I, (your full name) of (your address) am of sound mind and: I understand the importance and purpose of this Statement of Choices. I know this Statement of Choices will ONLY be used to guide future medical decisions when/if I lose the ability to make or communicate my medical treatment choices myself. I understand that it is very important for me to discuss and share my wishes with my family, appointed substitute decision maker/s (attorney/s) and health care providers. I ask that the choices and guidance provided in this document and discussed with my substitute decision maker/s, attorney/s be respected and followed. Regardless of all decisions about cardiopulmonary resuscitation and life prolonging treatments I know doctors will always try to speak with my chosen substitute decision maker/s attorney/s at the time a decision is needed. I understand I will receive all care to relieve pain and suffering. I may complete all or part of this document and know that I can change my mind regarding these choices at any time. I can add additional pages if necessary. I give permission for this document to be shared with my health care providers. Cross out any of the above if not applicable I declare that the information completed in this Statement of Choices is a true record of my wishes on this date: Signature: \_ Witness Name: \_\_\_\_\_ Signature: \_\_\_\_ An interpreter assisted with the completion of this form **Review of my Statement of Choices.** This document remains in place until it is updated or withdrawn. Your wishes, condition and treatment options may change over time. It is a good idea to review this plan every few years or if your circumstances change. Sign below if there are no changes to your choices. If your choices change, you will need to complete a new document and provide a copy to the people and places you have nominated on page 1. **Review 1:** I have reviewed this ACP, and there is nothing I would like to change. Witness Name: Date: Signature: Signature: **Review 2:** I have reviewed this ACP, and there is nothing I would like to change. Signature: Signature: Witness Name: Date:

#### You can submit your completed Statement of Choices and other Advance care planning documents to:

#### My DHR

Add an advance care plan to My DHR

#### **Canberra Health Services**

Health Information Services PO Box 11 Woden ACT 2606 Fmail: CHS.CPFScanning@act.gov.au

#### My Health Record

Add an advance care plan to My Health Record

#### The Public Trustee and Guardian

If you have prepared an Enduring Power of Attorney ('EPA') with the Public Trustee and Guardian ('PTG'), advanced care documents may also be stored at the PTG, by emailing them to the ptg@act.gov.au

Your general practitioner, treating specialist and private hospital on admission

If you have difficulty reading a standard printed document and would like an alternative format, please phone 13 22 81.



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