Draft Advance Care Directive DIY Kit

Making your future health care and life choices known

This draft Do-it-Yourself Advance Care Directive Kit contains:
General information
Step by step guide
Draft Advance Care Directive form

Advance Care Directives Act 2013 (SA)
The New Advance Care Directive

The Advance Care Directives Act 2013 (SA), commencing 1 July 2014, will empower adults to make clear legal arrangements for their future health care, end of life, preferred living arrangements and other personal matters.


Once the Act commences on 1 July, 2014, adults who choose to, can:

- write down their wishes, preferences and instructions for their future health care, end of life, living arrangements and personal matters; and/or
- appoint one or more Substitute Decision-Makers to make these decisions on their behalf when unable to do so themselves.

This will be able to be done all on the one Advance Care Directive form.

To assist people to fill in their Advance Care Directive, a draft Do-it-Yourself Kit has been developed.

The draft Kit includes:

- general information
- a step by step guide to help people complete the form with suggested example statements they can write on the form
- the new draft Advance Care Directive form
- extra information for witnesses, substitute decision-makers and interpreters.

The example statements have been developed with the assistance of doctors, nurses, aged care staff, social workers and consumers.
Have your say

To make sure we get the DIY Kit right, we invite you, your colleagues, your families and friends to read through this DIY Kit, follow the instructions and have a go at completing the Advance Care Directive Form (on page 40). Then you can tell us if you think it is easy to use.

We would like to know if:

- The information is easy to understand.
- The step by step guide was easy to follow and helped you to fill in the draft Advance Care Directive.
- The draft Advance Care Directive form was easy to fill out.
- Whether you think the example statements were helpful or if you would like others to be included.
- What other information you might need to assist you write an Advance Care Directive.
- You have any other comments.

How to make a submission

You can provide your feedback online at www.yoursay.sa.gov.au/advance-care-directive.

Alternatively, you can answer the consultation questions at the back of this document and email or post them to:

Email: policy&legislation@health.sa.gov.au – Subject line: Advance Care Directive.

Advance Care Directive Consultation
Policy and Legislation Unit
Department for Health and Ageing
PO Box 287, Rundle Mall
Adelaide SA 5001

Closing date for your feedback 31 March 2014.

For more information please contact policy&legislation@health.sa.gov.au or phone +61 8226 6717.
Advance Care Directive Do-it-Yourself Kit

This draft DIY Kit contains:

General information about Advance Care Directives .................................................. 6
Step by step guide to completing your own Advance Care Directive ....................... 10
The draft Advance Care Directive form ....................................................................... 40
Checklist ................................................................................................................... 52
Extra information for you ........................................................................................... 54
Suggested list of fact sheets (to be developed prior to 1 July 2014) ......................... 57
Where to get help and advice .................................................................................... 58

Information for:

a. For substitute decision-makers ......................................................................... 60
b. For witnesses .................................................................................................... 64
c. For interpreters ................................................................................................. 67

Feedback form ......................................................................................................... 68
How to use this guide

You will find the Advance Care Directive form on page 40 of this Kit. Tear it out and keep it next to you as you read through this information.

You can fill in your Advance Care Directive on your own or you may wish to get help from someone close to you or visit a lawyer or a doctor for advice.

If you prefer to fill in your Advance Care Directive online please visit www.acd.sa.gov.au (after July 1, 2014).

Is English your second language?

If English is not your first language you can use an interpreter to help you complete the form. See page 67 for more information.
Your choice

Although you may not like to think about it, there could be times in your life when you are unable to make your own decisions, either:

- for a short time because of a sudden accident, or a serious mental health episode
- slowly over time because of dementia or similar condition
- permanently because of a sudden serious stroke or because you are in a coma.

If this happened to you

How would you want decisions to be made for you about your health care, living arrangements or other personal matters?

Who would you want to make decisions for you?

Your voice

Writing an Advance Care Directive can make it easier for others to know your wishes for your future health and lifestyle if they have to make these decisions for you because you are unable to make them yourself.

It may also give you peace of mind that your wishes are known and will be respected if others need to make decisions for you.
Explaining some key words

**Advance Care Directive** (called ACD in this guide): is a legal form for people aged over 18 years. It can record your wishes and instructions for *future health care decisions, preferred living arrangements and other personal decisions*. It can also be used to appoint one or more adults to make these decisions for you. An ACD takes effect (can only be used) if you are unable to make your own decision(s).

**To be legal you must only use the official ACD Form (see page 40 of this kit).**

**Health care**: can include medical treatment, surgery, medications, nursing care, dental treatment, podiatry, physiotherapy, mental health treatment, optometry, psychological therapy, Aboriginal health care, emergency care, occupational therapy, and other services provided by health practitioners such as alternative therapies.

**Residential and accommodation decisions** (called living arrangements in this guide): can include where you wish to live, whether to go into supported care, whether you prefer to have a view of the garden, live by the sea, live with others or on your own.

**Personal decisions**: can be about your pets, holidays, employment, personal grooming, relationships that are important to you and many other things.

**You can make your own decision if you can:**

1. Understand information about the decision.
2. Understand and appreciate the risks and benefits of the choices.
3. Remember the information for a short time.
4. Tell someone what the decision is and why you have made the decision.

If, in the future you are unable to do these four (4) things, it means you are unable to make the decision (sometimes called impaired decision-making capacity) and someone else will need to make the decision for you.

**Substitute decision-maker** (called SDM in this guide): an adult or adults you choose and appoint in your ACD to make decisions about your *future health care, living arrangements and other personal matters* when you are unable to make these decisions for yourself, whether only for a short time, or permanently.

**Person responsible**: is an adult(s) able to make health care decisions for you if you have not appointed a SDM in your ACD. It will usually be someone who is close to you and is available and wants to make the decision for you. **It could be several people in your family, or someone contacted by your health practitioner.**
Can I write an Advance Care Directive?
You can write an ACD at any stage of life: when you are young, older, healthy or unwell.

To write an ACD it must be your choice and you must:
• be 18 years old or over
• know what an ACD is
• know what it will be used for and
• know when it will be used.

What if I have other documents in place?
If you have already completed an Enduring Power of Guardianship, a Medical Power of Attorney or an Anticipatory Direction, these will continue to be legally effective after 1 July, 2014.

Important
Your ACD cannot be used to make financial or legal decisions for you – it is recommended that you also think about appointing an Enduring Power of Attorney to make decisions about your finances or legal matters.

Important
If you want to update your existing document(s), or make a new ACD, you must use the new ACD form (on page 40). The new ACD will replace these other documents after 1 July, 2014.
How to fill in the Advance Care Directive form

The draft ACD form can be found on page 40 of this kit.

➢ Tear out the ACD form and keep it next to you as you read through this kit.
➢ Take your time, you may wish to complete the form over several stages.
➢ You may wish to talk to those close to you before you start.
➢ Fill in the ACD form as you go using the tips on the side of the ACD form.
➢ You can use a pencil, but the final version must be in blue or black pen.
➢ Write clearly so it will be easy for others to read.
➢ First complete Part 1 – Personal details. **Do not sign it yet.**
➢ You can fill in all or some of Parts 2, 3, 4, 5, 6 and 7.
➢ Keep reading this kit and fill in the Parts you want to as you go.
➢ **Before it can be used, your form must be witnessed.** (Fact Sheet # Who can witness my ACD – to be developed)
➢ You have to sign your ACD in front of a witness.
➢ **Do not** fill in Part 8 at this time. This Part is to be completed in the future if the situation arises.

If you need help to complete the form, ask a family member or friend. There are organisations which can help you – See page 58.
Part 1: My personal details

Fill in your personal details following the tips on the ACD form.

**Do not sign it yet.**

You must sign your ACD in front of your witness.

**How long will my ACD continue to apply?**

Most people want their ACD to continue to apply until they die – please tick this box if this is what you want.

**Remember – you should review your ACD regularly especially if your circumstances change.**

You can choose for your ACD to apply only for a set period of time. To do this you will need to write the number of years you want it to apply for in the space provided on the ACD form.

**Do I want to appoint substitute decision-maker(s)?**

Read this information and then decide if you want to appoint one or more SDMs.

- If you appoint one or more SDMs in your ACD you will have someone you trust and with the authority to make decisions for you if decisions need to be made for you.
- Having a SDM can help to avoid family conflict by making it clear who you want to make decisions for you and how.
- You can make sure the culturally appropriate person(s) for you have authority to make decisions by appointing them in your ACD.
- You can choose what types of decisions they can make (using the tick boxes on the form).
- You can tell your SDMs how you want them to make decisions for you, for example if you have more than one, if you want them to make decisions together or separately (see Part 2(c) Condition of appointment, page 17).
What is the difference between a substitute decision-maker and a person responsible?

**Substitute decision-makers (SDMs):**

- Are people you choose to appoint and you trust to make decisions about your health care, living arrangements, and personal matters for you when you are unable to make your own.
- Could be a person(s) with authority in your culture or family to make decisions for you, for example an Aboriginal Elder.
- Are people with authority over others (including persons responsible) to make decisions for you.

**Person responsible:**

- Can make health care decisions for you, but may not be able to decide about your living arrangements or other personal matters.
- Are usually family members or people close to you, available and who want to make the decision(s).
- Could be many people in your family – would they know what your wishes are and all agree on one decision?
- May not be the person or people you prefer to make decisions for you.
- Could be someone who does not know you well.

**Recommendation**

For your peace of mind, it is good to appoint one or more SDM’s, tell them what is important to you, and write down your wishes on the ACD form, so they and others know what you want.

**Important**

A person responsible, including a guardian appointed for you by the Guardianship Board, must follow any relevant wishes or instructions you have written in your ACD.
If you do not want to appoint anyone in your ACD, you can just write down what is important to you such as your culture, beliefs, wishes and instructions for your future health care, your dying wishes, where you wish to live and other personal wishes.

In some cases, particularly if there is disagreement about decisions, the Guardianship Board (or Tribunal) may need to appoint a guardian for you to make decisions about your health or living arrangements.

How do I pick my substitute decision-maker(s)?

Choose a person who:
- is 18 years or over
- has decision-making capacity
- knows you well
- you trust
- respects what is important to you
- can work out what decision you would make
- can be there when decisions are needed or can be contacted when needed
- can make serious decisions for you during an emotionally difficult time
- wants to be your SDM and understands what this means.

You cannot appoint someone who is paid to care for you such as your doctor, nurse or a professional carer (such as the Director of Nursing in an aged care facility or community care worker).

Scenario

Although Johann (70) had an ACD he had not appointed a SDM. When Johann was sent to hospital, he was living alone and had no close friends or family. As Johann had no one to make decisions for him and he could not make them himself, the hospital staff applied to the Guardianship Board for a guardian to be appointed to make sure his wishes and instructions in his ACD could be followed.

Scenario

Ming (37) decided he wanted to appoint one Substitute Decision-Maker in his ACD as he thought his mum (who would probably be his person responsible as she was his only living relative) would not be able to make decisions for him if he was ever badly hurt or sick. He decided to pick his best mate Sam who he had spoken to about his life and what was important to him.
How many Substitute Decision-Maker(s) should I have?

It may be good to have more than one SDM. Doing this means that:

• more than one person is prepared and able to make decisions for you if needed in the future
• another person is available should one unexpectedly become unwell, change their mind or die.

What are my options for appointing SDMs?

You can:

• appoint one SDM to make all your decisions
• appoint two or more SDMs and write down what types of decisions they can make
• appoint two or more SDMs and request that they make all decisions together
• appoint two or more SDMs and allow them to make decisions either together or separately.

It is up to you what you decide to do, and will depend on your personal circumstances or family/cultural situation.

Scenario

Kayo (30) was beginning to recover from her serious injuries from a car accident. She was unable to make decisions during this time. She had appointed her close friends Georgia and Anh as her SDMs to make all decisions when she was unable. At first, Georgia and Anh agreed that Georgia would make all decisions for Kayo whilst she was not able to, as Anh was on holiday. Now, with Kayo’s health improving, Georgia didn’t want to make any more decisions. Kayo had decided to appoint them to make decisions either together or separately so Georgia handed over her role as SDM to Anh when she returned from holiday.
Your Substitute Decision-Maker(s) must agree to be appointed.

Talk to the person(s) you want to be your SDM. You need to be clear about:

• what types of decisions you want them to make for you and
• how you want them to make decisions for you.

The person(s) you choose to be your SDM must sign the ACD to say that they understand what it means to be your SDM and that they agree to be appointed.

What it means to be your SDM is explained in the Information for Substitute Decision-Makers (page 60 of this kit) so make sure your SDMs reads and understands this information before they sign your ACD form.

Scenario

Following a lengthy stay in hospital, assessments showed that Mrs Grace needed a high level of support and that she was unable to make this decision. Mrs Grace’s four Substitute Decision Makers could not agree about where Mrs Grace should live. The Office of the Public Advocate (OPA) was asked to help. With their help they were able to hear Mrs Grace’s wish to return home, consider information about her care and support needs and the level of community and family support available. They agreed that Mrs Grace could return home and also agreed to begin applying to several aged care facilities in case her accommodation needs changed.

Recommendation

Your SDMs should follow and respect what you write in your ACD. It is recommended that you talk to your SDMs and others close to you about your ACD.

If you do not wish to complete this section, put a line through this section.
If you want to appoint more than two (2) SDMs, you will need to use the online version of the ACD form which is available on the website.

If you decide not to appoint any SDMs, please put a line through this section.

If you have decided to appoint one or two SDMs, fill in Part 2a using the tips on the side of the form or ask your SDMs to fill in this section.

**Before their name(s) are written on your ACD form, have your SDMs:**

- Read the *Information for Substitute Decision-Makers* and understand the role (see page 60)
- Agreed to be appointed as your SDM.

Tick the type of decisions you want your SDM to make.
Part 2b: Alternative Substitute Decision-Maker(s)

In case one or more of your SDMs cannot make decisions for you because they are unwell, lose their capacity to make decisions or die, you can appoint an alternative SDM who will only make decisions for you if your SDMs cannot continue in their role.

Like your other SDMs, your alternative SDM will also need to understand the role, and sign that they agree to be your SDM.

If you wish to do this you will need to fill in Part 2b of the form using the tips on the side of the form.

If you do not wish to appoint an alternative SDM, please put a line through this part.
Part 2c: Conditions of appointment

On this Part of the ACD form you can write down how you want your SDMs to make decisions for you. This is called putting conditions on their appointment.

**If you appoint two or more SDMs you can decide whether you want them to make decisions either together or separately.**

If you do not tick any of the boxes, they will automatically be able to make decisions together or on their own.

- This will mean that if only one SDM can be contacted a decision can still be made, but if two or more are available they can make a decision together.

If you decide that you want your SDMs to make all decisions together, tick this box.

- This may make the decision making process slower as all SDMs will need to agree.
- There is also the chance your SDMs may not agree.

**Important**

A health practitioner is only responsible for contacting one SDM (whoever they can reach). Your SDM is responsible for contacting other SDMs if more than one is appointed.

**Scenario**

Aarti put a condition in her ACD that her close friends, who she appointed as her SDMs, must speak to Aarti’s brother, Raj, who lives in Victoria, about decisions. She hoped this would avoid any conflict with family members.
In this section you might wish to:

• Write down the names of people your SDM must to talk to when making decisions for you – for example family members, close friends, religious adviser or Aboriginal Elders.

• Write down the name of your Financial Attorney (someone you have appointed to make financial and legal decisions for you in an Enduring Power of Attorney) if you have one. Your SDM will need to speak to your Financial Attorney if a decision your SDM makes might affect your finances.

Scenario

As Kayo recovered from her serious injuries, it was going to take a long time before she would be able to make her own decisions again. Though Anh was Kayo’s Substitute Decision-Maker for health and other decisions, Kayo’s brother Takumi had been appointed as her Financial Attorney several years before to make decisions about her finances when she was unable to. Anh contacted Takumi and asked if they could discuss where it would be best for Kayo to continue her recovery, for example in a dedicated rehabilitation facility, at home with bought-in support, or at Anh’s house with finances to support her care.
Part 3: What is important to me

What is important to me

What makes your life good? Seeing family and friends? Listening to your favourite music? Your pets? Being in the garden? Living a full and active life? Being independent and not having to rely on others? Your culture? Your religion?

Writing down **what is important to you** about your life and health will help your SDMs, person responsible, health practitioners and others to make decisions for you about your care and life if you are unable to make your own decision(s).

What would you want others to think about when making decisions for you?

Consider these suggested statements – you may want to write one or more of these on your form or you may have words of your own you want to use.

Some suggested statements:

- **Relationships with my family and my friends are very important to me. I would like my family and friends to be involved in my life.**
- **I prefer my pets to be near me or continue to be able to see them.**
- **Being independent is important to me and I would prefer not to have to rely on others daily.**
- **My cultural traditions and community are important to me. I prefer to continue to be involved with my cultural community if possible.**
- **My religion is central to my life. My decisions are guided by my religious faith which is...**
- **I value my cultural identity and enjoy the company of those who speak my first language.**
- **I have spent my life in the gay and lesbian community and wish to continue such contact.**
- **Being alive is enough for me, even if I could not walk or talk and had to depend on others to do everything for me.**
What do you fear more than death?

There may be some things which you fear more than death.

Consider these suggested statements – you may want to write one or more of these on your form or use your own words.

Suggested statements:

- I don’t want to be bedbound or placed in a chair all day, or be dependent on others to get around.
- I would hate to lose my mind and not be able to recognise my family or friends or remember important past events.
- I worry about being alone and frail and not being able to call someone to help me. I need to be with other people who will look out for me.
- I dread losing control of my bodily functions.
- I am less afraid of death, than I am of dying over a long period of time, in pain and without dignity.

Scenario

David and Sally (both 55) were on the back verandah having a glass of wine. David was telling Sally about a work colleague who had been diagnosed with dementia. David said “If I ever get dementia, just put me down”. Sally was upset by this and said that she would never consider such a thing, especially as it was illegal. Sally asked David what he found frightening about dementia, because in her work as an aged care worker, she knew of many people with dementia who had good lives. David told Sally what he feared most about this. David and Sally talked more about these things over time which helped them both understand what was important to each other.
Part 4: My health care wishes

This Part of the ACD form is about your health and well-being. What you write here will help your SDM, person responsible or health practitioner make health care decisions for you when you cannot make them yourself.

You can write:

1. Your preferred outcomes of health care.
2. Outcomes you want to avoid.
3. Your health care instructions.
4. Refusals of health care.

Health care includes:

- medical treatment
- life-sustaining treatment
- surgery
- mental health treatment
- medications
- dental treatment
- maternity care
- emergency care
- podiatry (foot care)
- physiotherapy
- occupational therapy
- psychological therapy
- palliative care
- alternative therapies such as Chinese medicine

- **Life sustaining treatment** – treatment that keeps you alive but doesn’t improve your health, such as your heart being restarted (CPR), life support with machines keeping you alive, or renal dialysis, or antibiotics.
- **Comfort care** – care that will keep you comfortable and manage your pain, but will not cure your illness.
- **Palliative care** – care that aims to improve your quality of life, prevent suffering, manage your pain until the end, and support your family through the process and after your death.

Go to Part 5 to write down your end of life wishes.
Preferred outcomes of health care

It is very hard to know what health care you may want in the future especially if you are well and don’t know what health problems you might have later.

Sometimes when you are sick or hurt, having health care will mean that you get better and go back to the way you were before. For example – if you have a blood infection, antibiotics can often help cure this and get you back to the way you were before.

Other times health care can only help you a little and even though you may improve, you may not be able to live the same way as you did before. For example – you may need surgery to help relieve hip pain but after this you will not be mobile and may need help to dress yourself, shower, cook or need a wheelchair.

How you feel and what your life is like after health care is given is called an outcome of health care.

How you feel about an outcome of health care may be different if the outcome may only be for a short time or if it will be permanent. For example, if you have a serious stroke you may recover your mobility and ability to make decisions over time, or you may require permanent full-time care, possibly in an institution such as a nursing home.

Sometimes health care helps you but not the illness, such as health care for pain relief which does not cure your illness but lessens your pain.

Important

Remember this part is about any time when you are unable to make your own decision(s), not only at the end of your life. For example you may have a known mental illness or are permanently unconscious because of a car accident.

If you do not wish to complete this section, put a line through this section.
There may be outcomes of care which you might not want. For example would you want health care that:

- is likely to leave you unable to breathe without a machine?
- would leave you dependent on kidney dialysis machines?
- results in you living permanently in institutional care?
- is likely to leave you permanently unable to communicate or move around?

You may want to write down your preferred outcomes of care or outcomes of care which you wish to avoid.

**Consider these suggested statements – you may want to write one or more of these on your form or use your own words.**

Suggested statements:

- If I have a serious car accident or injury and I am not likely to recover, I would prefer comfort care to maintain my dignity.
- If I am in a permanent coma, and I am not likely to communicate meaningfully again, I do not want health care that keeps me alive and would prefer to be comfortable and allowed to die with dignity. I would like to donate my organs if possible.
- If I have a mental health episode I would prefer to be given my usual treatment at home and not be put into institutional care.
- If I am unable to shower and go to the toilet myself I want to be kept clean and dry and my dignity maintained.
- If I am unable to recognise family and friends and unable to communicate I do not want any health care which prolongs my life.
- If I have a serious brain injury I am happy to be alive and would accept all health care which is offered to me, even if such care leaves me with physical or mental disabilities.
- I would prefer that decisions are fully discussed with my SDMs.
- I want to live as well as possible for as long as possible and I am willing to accept medical treatment that my doctors and family think is appropriate.
- To help with my physical pain I would prefer Chinese medicine and meditation.

Important

It is not helpful to write vague statements like I don’t want to be a vegetable or I don’t want to be a burden on my family. These won’t make it easier for others to make decisions for you.
Health care I do and do not want

You may have clear wishes or instructions about specific health care (including medical treatment) you prefer or do not want.

Important

If you have a diagnosed condition and you want to write specific health care instructions, ask your doctor or specialist if what you want to write will be understood and have the result you want. (Fact Sheet # Talking to my doctor about my wishes – still to be developed).

When you need health care, health practitioners think about what is wrong with you and tell you what health care will help you or your illness.

There may be one choice of health care or many. Your health practitioner should clearly explain your health care options to you, your SDM or person responsible and what they will mean for your health and life. (Fact Sheet # Questions to ask your doctor – not yet developed)

You (in your ACD), your SDM or person responsible cannot tell your health practitioner what treatment to give you – this is called demanding treatment.

You are limited only to saying yes (consenting) or no (refusing) to the health care being offered by your health practitioner.

If you want to write health care instructions consider these suggested statements – you may want to write one or more of these in your form or use your own words.

Suggested statements

- If I am permanently unable to communicate, or recognise my family and friends, I only want medical treatment which keeps me comfortable.
- If I have a terminal illness I only wish to be put on a ventilator if it is only for a short time, such as overnight to help me breathe.
- If I have a mental illness and I am temporarily unable to make my own decisions, I prefer to be given my usual medications even if I refuse them at the time.
- I will accept all health care and medical treatment which will improve my health and give me more time with my family if appropriate.
- If I have dementia and I fall and break my hip I agree to surgery.
- I would prefer pain medications which do not leave me too groggy to talk with my family/friends.
Refusals of health care must be followed if relevant

If you do not want certain types of health care you can write this down in your ACD. This is called a refusal of health care.

If you do this it is important to make sure you write down when or under what circumstance the refusal applies (eg have severe pain after surgery you would prefer not to have morphine because it makes you vomit).

If you have refused specific health care in your ACD, your health practitioner cannot give you that health care because you have said no to it. If your SDM or person responsible says no to health care (because they believe it is the decision you would have made) – your health practitioner cannot give you that health care.

Important

A health practitioner can override a refusal of health care:

- if there is evidence to suggest you have changed your mind, but did not update your ACD, or
- the health practitioner believes you didn’t mean it to apply to the current circumstance.

If this happens the health practitioner will need consent from your SDM if you have one, or a person responsible.

Scenario

Billy (42) wrote in his ACD that he didn’t want any antibiotics. Billy got a bladder infection and was in great pain and could not make his own decisions. His doctor questioned whether the refusal was meant to apply. His doctor spoke to his SDM and discovered that Billy actually only wanted the refusal to apply if he had a terminal illness not when he was fit and well.
If you want to write specific refusals of health care, medical treatment or life-sustaining treatment, consider these suggested statements –

**You may want to write one or more of these in your form or use your own words.**

**Suggested statements**

- If I am permanently unable to communicate, I do not wish to have any medical treatments that will prolong my life. Please give me palliative care.

- I do not want to have my heart started if it stops at any stage of my life. I would prefer to die quickly.

- I do not want my limbs amputated, even if it would save my life. I prefer to die with my limbs in-tact.

- If I am permanently living in institutional care or requiring 24 hours a day care, I only want health care to make me comfortable and which doesn’t prolong my death.

- If my heart stops at any time in my life I do not wish to be brought back to life.

**Important**

You cannot refuse compulsory mental health treatment, for example listed in a community treatment order if you have one.

**Scenario**

Katerina (30) had a recurring mental illness. Sometimes she was well and sometimes she went off her medicine and became unwell. She knew that medicine X had terrible side-effects but medicine Y did not. She wrote in her ACD that she wanted medicine Y but not medicine X if she ever became unwell. Katerina was glad she could make her wishes clear in her ACD in case she couldn’t tell her doctor at the time.

**If you do not wish to complete this section, put a line through this section.**
Part 5: My dying wishes

On this Part of the ACD form you can write about what will be important to you and your health care wishes for the end of your life.

What you write here will help your SDM, person responsible, health practitioner and others make decisions for you if you cannot and you are at the end of your life.

My dying wishes

Thinking about your wishes for the end of your life is hard to do. Think about what would be most important to you at this time.

You may want to write down:

- Situations you want to avoid or that would be unacceptable when you are dying.
- Where you would prefer to die (at home, or in your aged care facility or hospital).
- Who you would want to be there.
- What or who is important to you at the end of your life.
- Your spiritual/religious needs and wants.
- Cultural traditions that are important to you.
- Aboriginal and Torres Strait Islander practices that you want followed eg Return to Country.
- Your organ and tissue donation wishes in case you die in circumstances where this is possible. www.donatelife.gov.au
- Burial or cremation wishes.
- Your funeral arrangements.

Important

Your wishes should be followed by your SDM, person responsible, health practitioner and others if it is possible to do so. It may not be possible because of available services or your financial situation.
If you want to write down what will be important to you and any other wishes for when you are dying, consider these suggested statements –

**Suggested statements**

- I want more time with my family.
- I would prefer to have better quality of life for a shorter time.
- I would prefer a quick pain-free death.
- It is important that I have time to say goodbye if possible.
- I would rather be alone and have time for quiet reflection.
- I want to have the support and involvement of family or friends at this time.
- I want to be in a comfortable, familiar environment surrounded by my memories.
- When I am dying I would like my favourite music playing in the background and the room lit with soft light/candles.
- When I am dying, please make sure my room is full of happiness and joy – I want people to celebrate my life and not mourn my dying.
- If I can, I want to donate my organs and tissues.
- My spirituality is important to me so please let nature take its course and just make sure I am comfortable.
- My religion is important to me and I want my religious adviser contacted (provide contact details on your ACD form).

---

**Scenario**

Edward (87) had been in his nursing home for the past four years and it had become home to him. Edward had an ACD and he had written that he wanted to die where he lived, have his children present and his favourite music playing. Edward deteriorated over the next three weeks. Because his wishes were known he died peacefully in the nursing home surrounded by his large family.
My health care wishes when I am dying

You may want to write down your wishes or instructions about specific health care for when you are dying.

You may also want to write down your wishes about:

- **Life sustaining treatment**
- **Comfort care**
- **Palliative care**
- **Being transferred to hospital.** (See page 21 for what these terms mean)

### Refusals of health care must be followed if relevant

**Recommendation**

If you refuse certain types of health care in your ACD, including life sustaining treatment, you need to make sure you write down the kinds of circumstances the refusal applies to.

If you have written health care you do not want at this stage of your life, your health practitioner cannot give you that health care because you have said no to it even if it means you will die.

If your SDM or person responsible says no to health care (because they believe it is the decision you would have made) – your health practitioner cannot give you that health care even if it means you will die.

You cannot request voluntary euthanasia or anything illegal in your ACD.

### Important

You (in your ACD), your SDM or person responsible cannot demand that health care be given to you even when you are dying.
If you want to write health care wishes or refusals of health care for the end of your life, consider these suggested statements – you may want to write one or more of these on your ACD form or use your own words.

Suggested statements

- If I have a terminal illness and I am dying, I do not want any life-sustaining treatments. Please keep me comfortable.
- I live in an aged care home and I have several health problems. If I collapse or my heart stops, I don’t want to be transferred to hospital if I can be kept comfortable where I am.
- If I am dying, I do not want to be transferred to hospital unless my comfort and dignity cannot be maintained in my home/nursing home.
- I do not want to be fed by a tube, even if this means I may die. I only want to be offered foods and fluids by mouth.
- If I am permanently unable to communicate and make my own decisions, for example because of dementia or a serious stroke, I do not want any treatment that would leave me with worse symptoms even if it means I will live longer – I only want treatment that improves my physical and mental health and to be kept comfortable.
- I want time to say goodbye to my family (who are overseas) if possible so please try and keep me alive so my family can see me before I die.
- If I have a serious condition for which I am not going to recover, I am incontinent, cannot eat without assistance and I am dependent on others to wash and move me, I do not want any treatment which prolongs my death. Please keep me comfortable where I live if possible.

Scenario

Lucia (85) had an extensive history of heart disease as well as previous care for serious stomach problems. She went to the Emergency Department (ED) with severe pain, and couldn’t make her own decisions. Lucia had made it clear in her ACD that she only wanted comfort care in this situation. The ED staff accepted her refusal of health care and wishes, set her up in a separate room on the ward where her family could be with her and she died 36 hours later surrounded by her family, without pain, and in the manner she preferred.
Part 6: Where I wish to live and my personal wishes

On this Part of the ACD form you can write down your future wishes about where you wish to live or other personal preferences such as who you prefer to look after your pets if you cannot, or relationships that are important to you.

Whether your wishes can be followed might depend on your personal and financial situation or available services. If you have appointed a Financial Attorney, your SDM (if you have one) may need to speak to them before making a decision for you.

Where I wish to live

In the future you might not be as independent as you are now and you might need:

- To be supported to live independently with in-home care and support.
- Care by family, friends or professionals.
- To be looked after in a disability or aged care facility.
- Temporary care or support or a permanent or long term arrangement.

Writing your wishes here helps your SDM and others who may need to make decisions for you, such as your family or a guardian if one has been appointed for you, make decisions about where you should live or be cared for when you cannot make this decision(s) yourself.
Consider these suggested statements – you may want to write one or more of these on your form or use your own words.

- I prefer to be supported and cared for at home for as long as possible.
- I prefer to live with my family for as long as possible.
- I prefer to maintain my independence for as long as possible.
- I prefer to live close to family and friends so they can visit me easily.
- I prefer to live where my spiritual needs will be met.
- I prefer to live somewhere where they respect my sexuality.
- I prefer to live in a place where the staff speak my language.
- I prefer to live where my treatment and care can be provided to me.
- I prefer to live somewhere that has a garden or is near the beach.
- I prefer not to live in an institution if possible.

**My personal wishes**

There may be some activities, interests or hobbies which are important to your life. Write these down on your ACD form so that others know and can help you continue doing these things if possible.

**Suggested things to consider**

- activities you enjoy and prefer to keep doing if you are able to, such as walking, gardening or singing in a choir
- things you don’t like to do, such as playing bingo or long car drives
- organisations or groups that you belong to and want to continue with
- relationships that are important to you
- your favourite music
- being able to use the internet (if possible)
- who you prefer to spend holidays with
- people who you do or do not want to visit you
- what kinds of clothing you prefer to wear or not to wear, for example I do not want to wear tracksuits at any time of the day or night
- what you prefer to happen with your pets if you need supported care
- flowers you like that don’t make you sneeze
- how often you want your hair cut and who usually cuts it
- other grooming requirements such as removal of facial hair
- church, religious or cultural ceremonies.
You can also provide advice about other personal matters such as:

- church, synagogue, temple or mosque you attend
- sexuality
- personal dress standards.
- others?

**Recommendation**
Filling in this part of the form will help others, who may be making decisions for you or caring for you, know your likes and dislikes. Remember you may not be able to tell them yourself in the future.

😊 **Good news...you are nearly finished, just a few more things to do**

If you do not wish to complete this section, put a line through this section.
Part 7a: Witness statement

Your ACD is not legal until you have signed it in front of an independent witness and your witness has signed it. Both you and the witness will need to initial each page of the form in the space provided.

Important

For the full list of witness categories see Fact Sheet # – who can witness my ACD (to be developed) (will be dependant on regulations) and includes:

- Registered professionals such as teachers, nurses, doctors or pharmacists.
- Lawyers or Justices of the Peace (JP)
- Local, state or commonwealth government employees (with more than 5 years service)
- Bank managers or police officers (with more than 5 years service)
- Ministers of religion.

Your witness must fill in and sign Part 7a of the ACD form.

Your witness must be independent of you and cannot be:

- A beneficiary in your will (for example a family member or someone who you will leave money or personal items to)
- A person appointed as your SDM or
- Your health practitioner or someone paid to care for you.

There are many professional groups who can witness your ACD – this means finding a witness should be easy.

By having your ACD witnessed, it means that health practitioners and others can rely on your ACD.

The witness has to make sure that:

- You know what an ACD is, what it will be used for and when it will apply.
- You want to have an ACD and no one is making you have one.

The witness will want to speak with you on your own or with an interpreter present if you are using one, to check these things. They will ask you some questions.

Your witness will want to know if you have read and understood the information in this Kit.
When your ACD is witnessed, you will need to show proof of who you are (your ID) such as a drivers licence, passport or concession card or a card or document with your name, address and signature.

For more information see the Information for Witnesses section on page 64.

Making certified copies of my ACD

The witness can help you make certified copies of your ACD at the same time as they witness your original ACD form. This will be important so that you can give your SDMs, others close to you, your doctor or other health practitioners a certified copy of your ACD.

There is space on the front of the ACD form for the witness to fill in when they certify each of the photocopies.

For more information see the Information for Witnesses in the extra information section on page 64.

Important

Your ID will be checked by the witness so it is important that the details on your ID match your personal details on the form.

Important

When your ACD is completed and signed by you, your SDM (if you have one), and your witness (and interpreter if you have used one), make photocopies of the ACD. The witness can certify all copies as a true copy of the original.

Important

To make decisions your SDM must show your doctors, health practitioners or aged care staff an original or certified copy of your ACD to prove that they have the authority to make these decisions for you when you are unable to make your own.
Part 7b: Interpreter statement

If English is your second language, and you have used an interpreter to help you write your ACD in English, your interpreter must complete this section of the ACD form.

Please make sure your interpreter reads the Information for Interpreters section on page 67.

If you have not used an interpreter please put a line through this part.
Part 8a: Resignation of Substitute Decision-Maker

You will only need to fill in Part 8(a) of your ACD form if your SDM wants to step down from their role because they are no longer able or willing to make decisions for you – for example because they are sick.

If you are still able to complete a new ACD (you know and understand what an ACD is and what it will be used for) and your SDM steps down from the role you can:

- Fill in Part 8a of the ACD form with your resigning SDM:
  - If you do not have any other SDMs your ACD can still be used on its own. You will need to rely on your person responsible to make health care decisions for you when you cannot.
  - If you have appointed more than one SDM, the remaining SDM can continue to make decisions for you.

- Fill in part 8b of the ACD form – this will cancel your ACD.
  - You can then choose to fill in a new ACD form appointing a new SMDs.
  - See Fact sheet: Cancelling my Advance Care Directive – Part 8b (to be developed)

If the time comes when you do not know or understand what an ACD is and what it is used for and your only SDM wants to resign, they have to seek permission from the Guardianship Board.

See page 58 of this Kit for contact details.
Part 8b: Cancelling my Advance Care Directive

You cannot alter your ACD once it has been finalised and signed by you and a witness. If you want to change your ACD or appoint a new SDM you will need to cancel (revoke) your original ACD and fill in a new ACD form.

You can cancel your ACD if you still understand what an ACD is, what it will be used for and when it will apply.

To cancel your ACD you will need to fill in Part 8b of the ACD form in front of a witness. The witness must be someone from the list of witnesses on page # (to be developed).

If you:

- write a new ACD, give certified copies of the new ACD to appointed SDM(s), family, health practitioners and anyone else who has a copy of the old one.
- cancel your ACD but don’t write a new one, give a copy with the revocation section completed to everyone who has the original.

If the Guardianship Board decides that you really want to cancel your ACD, you understand what would happen and it is the right decision for you, then the Guardianship Board will cancel it for you.

If the Guardianship Board decides you need a guardian appointed for you, then the guardian must respect any wishes and instructions you have written in your ACD.

Important

If you are no longer able to complete a new ACD because you do not meet the requirements (eg you are not able to understand what an ACD is and what it will be used for) and it is unclear whether you understand what would happen if you did this, the Guardianship Board can be asked to consider your decision.

Only fill in this section when you want to cancel your ACD.
Advance Care Directive form

The final version of the Kit will include a tear out copy of the form.

The final Kit will also include a completed example ACD form.
Advance Care Directive

Part 1: Personal details

I, ____________________________________________________________

(Full name of person making this Advance Care Directive)

of __________________________________________________________

(current address of person making this Advance Care Directive)

Ph: __________________________ ☎ Date of birth: __/__/____

do hereby give this Advance Care Directive.

In doing so I revoke all other Advance Care Directives, Enduring Powers of Guardianship, Medical Powers of Attorney and Anticipatory Directions previously given by me.

I have read the Kit, understand the legal effects of giving this Advance Care Directive and am doing so of my own free will.

Signed __________________________ Date: __/__/____

(Signature of person making this Advance Care Directive)

I understand that this Advance Care Directive will only be used, and my appointed Substitute Decision-Maker (if any) will only make a decision for me when I do not have the capacity to make a decision myself.

Unless revoked and pursuant to section 16 of the Advance Care Directives Act 2013 (SA), this Advance Care Directive is in force upon signing and will continue:

☐ until death

☐ other period ...........(years)
Part 2a: Appointing Substitute Decision-Makers

The following person has been appointed to make decisions for me when I cannot do so myself whether temporarily or permanently:

I appoint: _____________________________________________________________

(Name of Substitute Decision-Maker)

to make the following decisions on my behalf (please tick):

- [ ] All my decisions
- [ ] Health care decisions
- [ ] Residential decisions
- [ ] Personal decisions

____________________________________________________________

____________________________________________________________

I, ________________________________________________________________

(Name of appointed Substitute Decision-Maker)

of ______________________________________________________________

(Current address of appointed Substitute Decision-Maker)

Ph: ______________________ ☎

have read, understand and accept my role and responsibilities as Substitute Decision-Maker as set out in the Information for Substitute Decision-Makers.

Signature ___________________________ Date: ___ / ___ / ______

(Signature of appointed Substitute Decision-Maker)
The following person has been appointed to make decisions for me when I cannot do so myself whether temporarily or permanently:

I appoint: ______________________________________________

(Name of appointed Substitute Decision-Maker)

to make the following decisions on my behalf (please circle):

- All my decisions
- Health care decisions
- Residential decisions
- Personal decisions

I, ______________________________________________

(Name of appointed Substitute Decision-Maker)
of ______________________________________________

(Current address of appointed Substitute Decision-Maker)

Ph: __________________________ ☎

have read, understand and accept my role and responsibilities as Substitute Decision-Maker as set out in the Information for Substitute Decision-Makers.

Signature __________________________ Date: _____ / ____ / ______

(Signature of appointed Substitute Decision-Maker)

To appoint more than 2 SDMs please complete the form online.

If you do not fill in this Part please draw a line through this section.
Part 2b: Alternative substitute decision-maker

If one of the above person/s are unable or no longer want to make decisions for me,

I appoint: ______________________________________________________

(Name of alternative Substitute Decision-Maker)

to make the following decisions on my behalf (please tick):

- All my decisions [ ]
- Health care decisions [ ]
- Residential decisions [ ]
- Personal decisions [ ]

I, ________________________________________________________________

(Name of alternative Substitute Decision-Maker) of ______________________________

(Current address of alternative Substitute Decision-Maker)

Ph: ____________________________ ☎

have read, understand and accept my role and responsibilities as alternate Substitute Decision-Maker as set out in the Information for Substitute Decision-Makers.

Signature __________________________ Date: __ / __ / ______

(Signature of alternative Substitute Decision-Maker)

Part 2c: Conditions of appointment

General Conditions:

____________________________________________________________

____________________________________________________________

____________________________________________________________

Only fill in this Part if you have appointed 2 or more Substitute Decisions-Makers to make the same type of decision for you

When making decisions for me, my Substitute Decisions-Makers can make decisions (please tick):

- Separately [ ]
- Together [ ]
- Other [ ] (please specify): ____________________

Part 2c

This Part is optional.

Read page 17 of the Kit for more information on writing conditions of appointment.

If you do not fill in this section your SDMs will be able to make decisions together and separately.

If you do not fill in this Part please draw a line across it.
Part 3: What is important to me

When decisions are being made for me I want people to consider:

What is important to me:

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________

What I fear more than death:

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________
Part 4: My health care wishes

When health care decisions are being made for me I want people to consider:

**My preferred outcomes of health care**

____________________________________________________________

____________________________________________________________

____________________________________________________________

____________________________________________________________

____________________________________________________________

____________________________________________________________

**My health care instructions – should be followed if possible**

____________________________________________________________

____________________________________________________________

____________________________________________________________

____________________________________________________________

____________________________________________________________

**My refusals of health care – must be followed if relevant**

*(to make sure your refusals of health care are followed you must state when and in what circumstances they apply)*

____________________________________________________________

____________________________________________________________

____________________________________________________________

____________________________________________________________

____________________________________________________________

____________________________________________________________

These instructions will help your SDM, person responsible and health practitioner make a decision for you.

Your health care instructions should be followed if it is possible to do so.

Your health practitioner must follow your refusal of health care if it is relevant to the decision being made.

If you do not fill in any of these Parts please draw a line through the blank sections.

Your initial □  Witness initial □
Part 5: My dying wishes

When decisions are being made for me at the end of my life I want people to consider the following:

My dying wishes

____________________________________________________________
____________________________________________________________
____________________________________________________________
____________________________________________________________
____________________________________________________________

My health care wishes

My health care instructions for when I am dying should be followed if possible

____________________________________________________________
____________________________________________________________
____________________________________________________________
____________________________________________________________
____________________________________________________________

My refusals of health care must be followed if relevant

(to make sure your refusals of health care are followed you must state when and in what circumstances they apply)

____________________________________________________________
____________________________________________________________
____________________________________________________________
____________________________________________________________
____________________________________________________________

If you do not fill in any of these Parts please draw a line through the blank sections.
Part 6: Where I wish to live & my personal wishes

Where I wish to live:
When decisions are being made for me about where I live I want people to consider:

________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________

My personal wishes
When decisions are being made for me I want people to think about the following:

________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________

If you do not fill in this Part please draw a line across it.
Part 7a: Witness statement

Pursuant to section 15 of the Advance Care Directive Act 2013 (SA)

I, ___________________________________________________________

(Full name of witness)

of __________________________________________________________

(Current address of witness)

Ph: ___________________________☎ ___________________________

(occupation of witness)

certify that I have:

☐ explained the effects of giving an Advance Care Directive to the person giving this Advance Care Directive

and am satisfied:

☐ the person understands the information in the Kit and the explanation given and

☐ the person giving the Advance Care Directive did not appear to be acting under any form of duress or coercion.

I declare that I meet the witness requirements under the Advance Care Directives Act 2013 (SA) as set out in the Witness Information.

Signed____________________________ Date:_____/___/_______
Part 7b: Interpreter statement

Pursuant to section 14 of the Advance Care Directive Act 2013 (SA)

I,___________________________________________________________

(Full name of interpreter)

of____________________________________ Ph: ______________

(Current address of interpreter)

certify that I have:

☐ Explained the information in the kit to the person and

☐ the information recorded in the Advance Care Directive form accurately reproduces in English the original information and instructions of the person

and am satisfied:

☐ the person understands the information in the Information Guide.

Signed_____________________________ Date:___ / ___/ ______

(signature of interpreter)

Interpreters:

Please read the Information for Interpreters on page 67 of the Kit.

If you used an interpreter they will need to fill in this Part.

If you did not use an interpreter please draw a line through this Part.
Part 8a: Resignation of my Substitute Decision Maker

Only to be completed by your Substitute Decision-Maker if they wish to resign.

I, ______________________________________________________________

(Name of resigning Substitute Decision-Maker)

of ______________________________________________________________

(Current address)

Ph: __________________________☎

renounce my appointment as Substitute Decision-Maker under this Advance Care Directive.

Signature ___________________________ Date: ____ / ____ / ______

(Signature of Substitute Decision-Maker)

Signature ___________________________ Date: ____ / ____ / ______

(Signature of person who gave this Advance Care Directive)
Part 8b: Cancelling my Advance Care Directive

Do not complete this section unless you wish to cancel (revoke) your Advance Care Directive.

Person statement

I, ________________________________________________________________

(Full name of person who gave this Advance Care Directive)

of ______________________________________________________________

(Current address of person who gave Advance Care Directive)

understand the consequences of revoking this Advance Care Directive and do so pursuant to section 29 of the Advance Care Directives Act 2013 (SA)

Signature __________________________ Date: ___ / ___ / ______

(Signature of person who gave this Advance Care Directive)

Witness statement:

I, ________________________________________________________________

(Full name of witness)

of ______________________________________________________________

(Current address)

Ph: _____________________________☎______________________________

(Occupation of witness)

certify that I am satisfied that the person who gave this Advance Care Directive is competent and understands the consequences of revoking this Advance Care Directive.

Signature __________________________ Date: ___ / ___ / ______

(Signature of witness)
Checklist

This is for your own personal use and not a requirement. Checking off things as you go or when you are finished filling in the ACD form may be helpful.

☐ I have read and understand the Kit.
☐ I am 18 or over.
☐ I understand what an ACD is, what it will be used for and when it will apply.
☐ I need an interpreter or a support person to help me fill in the form.
☐ I have discussed this with people close to me.
☐ I am ready to complete my ACD form.
☐ I have decided to just write instructions and rely on my person responsible to make decisions for me when I cannot.
☐ I understand that if other decisions are needed about my living arrangements a guardian may be appointed for me by the Guardianship Board.
☐ I have decided to appoint/not appoint my own SDM.
☐ I have decided to appoint more than one SDM and know who I want.
☐ I have spoken to my SDM(s) about appointing them and they have agreed.
☐ I think I need to check what I have written in my ACD with my doctor/lawyer before I get it witnessed.
☐ I have found a witness who can witness my ACD.
☐ I understand that before it can be used I must sign the ACD in front of my witness and they must sign it too.
☐ My witness and I have initialled each page.
☐ My witness has made certified copies.
☐ I have given certified copies of my ACD to my SDM(s), doctor, family, friends etc.
☐ My ACD is kept _________.

Advance Care Directive DIY Kit
Section 3: Information you and others need to know

When will my Advance Care Directive (ACD) be used?

Your ACD will only be used and your Substitute Decision-Maker (SDM) will only make decisions for you, when you cannot decide things yourself.

If you do not have a SDM, your ACD will be used by those making decisions for you such as persons responsible, health practitioners, or aged care staff.

Can you make your own decision?

Factsheet # What does it mean to have decision-making capacity (to be developed) can help your SDM and those close to you work out whether you are able to make your own decision or whether someone else will need to make it for you.

Non-urgent decisions

If you will not be able to make your own decision for a short time – for example waiting for the effects of medication to wear off – a decision should wait until you can make it yourself.

Seeking help to work this out

If your SDM is unsure if you can make a particular decision, the Office of the Public Advocate can be contacted for advice (Fact sheet # Helping to solve problems – not yet developed).

Your doctor may also be able to help work out whether you have the ability to make the decision yourself although it is not necessarily a medical assessment.
What do I do with my finished ACD?

You have finished writing your ACD and it is all signed and witnessed. It is important that others know you have written an ACD, especially in case of an emergency.

- Keep your original ACD in a place where you and others can find it easily.
- Write down where you have kept it so you do not forget.
- Your ACD is a personal document, but it is not private.
- Do not keep your ACD with your Will – people will only look at your Will after you die. You want people to know your wishes before you die.

You should:

- make certified copies with your witness
- give a certified copy to your SDM(s)
- give certified copies to those who care about you and care for you, such as your family, close friends, GP, doctor and any other health practitioner you regularly visit
- take a certified copy with you if you go to a hospital, hospice or aged care facility, or if you travel interstate or overseas
- put a note on your fridge or notice board about the location of your ACD and the name and contact details of your SDMs (if you have one)
- complete the card in this Kit and put it in your wallet or purse (to be developed).

In the future your ACD may be uploaded onto an electronic medical record at your local hospital, aged care facility, GP office or onto your Personally Controlled Electronic Health Record (see page 59 for more information).

Important

Review your ACD often. Life is full of changes and if you become sick or your circumstances or those of your SDM change, you may want to review and make a new ACD if you are still able to do so.

Important

Even if you decide not to appoint a SDM, but fill out the rest of the ACD, make sure you give copies of the ACD to those close to you who may be called upon as the person responsible, your health care practitioners, your hospital, GP, upload it on your Personally Controlled Electronic Health Record. If you do this, people will know your wishes when needed.
What should those caring for you do?

• Ask you if you have an ACD.
• Ask for a certified copy to keep in their file.
• Discuss your ACD with you and what it means for you and your future wishes.
• When you are unable to decide, those caring for you should:
  – try to help you make your own decision if possible
  – read your ACD and follow any relevant wishes or instructions you have written
  – consult your SDM(s) (if you have appointed one) or your person responsible. It is not their responsibly to contact all SDM(s), only the first one they can reach. It is up to your SDM(s) to contact others if more than one is appointed.
  – give advice to your SDM or your person responsible about what options there are for you.

What happens if there are problems with my ACD?

Problems may arise in the future about what you have written in your ACD, or who you have appointed as your SDM(s).

Recommendation

To avoid problems, talk to your family and friends about your ACD so that everyone is clear about the decisions you would want made for you and who you want to make them, when you are unable to make them yourself.
Important
The Office of the Public Advocate can:

- help work out whether you can make your own decision or whether your ACD should be used
- help you, your SDM, health practitioners or others close to you solve problems if there is disagreement about a decision being made for you.
- they can help you and those close to you make a decision together.

Contact the Office of the Public Advocate on: (08) 8342 8200 for advice or assistance, or visit their website: www.opa.sa.gov.au.

As a last resort, the Guardianship Board can resolve disputes using a legal process.

Contact the Guardianship Board on: 1300 555 727, or visit their website: www.guardianshipboard.sa.gov.au.

Important
When solving problems, your wishes are the most important.

Scenario
Mr May’s three SDMs did not get along and didn’t want to talk with each other even though they had successfully made joint decisions in the past. Mr May could not make his own decisions due to advanced dementia but he clearly stated in his ACD that he wanted a relationship with all three SDMs. One of the SDMs asked the OPA to help them work out how they could work together for Mr May. The SDMs agreed to a visiting schedule that avoided contact with each other on a day to day basis. They also discussed how they would come together to consider any future decisions that arose for Mr May, and agreed a plan to do so, ensuring that Mr May would be included to the full extent of his abilities.
Series of Fact Sheets

Yet to be drafted and more to be added.

This Kit has referred to fact sheets. These have not yet been developed but will be available as part of the final Kit and on the website (after 1 July, 2014).

This is a suggested list.

1. What does it mean to have impaired decision-making capacity?
2. Who is a person responsible and what is their role?
3. Questions to ask my doctor.
4. Who can witness my ACD?
5. Role of the Office of the Public Advocate – Advice and Dispute Resolution.

What other Fact Sheets would help you with your ACD?
Where can I get more information?

**ACD website (after 1 July):**
- Fact Sheet series
- How to find a witness
- Guideline for witnesses
- Finding an Interpreter
- Resources for consumers (eg peer mentor e-learning module)
- Resources for professionals (eg e-learning module; information for health practitioners, information for lawyers; aged care workers)
- *Advance Care Directives Act 2013* (SA)

**Legal Services Commission**
- For advice or help to write your Advance Care Directive.
- Witnessing your Advance Care Directive.
- Contact:
  - 1300 366 424

**Office of the Public Advocate**
- For advice and help about the application of ACDs contact
- To help solve problems
- Contact:
  - 08 8342 8200
  - Country SA only: 1800 066 969

**Guardianship Board**
- To resolve disputes
- Contact:
  - 08 8368 5600
  - Country SA only: 1800 800 501
Aged Rights Advocacy Service
• Contact:
  www.sa.agedrights.asn.au
  08 8232 5377
  Country SA only: 1800 700 9600

Council of the Ageing
• Contact:
  www.cotasa.org.au
  08 8232 0422
  Country SA only: 1800 182 324

Seniors Information Service
• Contact:
  www.seniors.asn.au
  08 8168 8776
  Country SA only: 1800 636 368

Palliative Care Council of South Australia
• Contact:
  www.pallcare.asn.au
  08 8271 1643

Personally Controlled Electronic Health Record
• Contact:
  www.ehealth.gov.au/internet/ehealth/publishing.nsf/content/home

Advance Care Planning assistance
• Email: RespectingPatientChoicesAdministration@health.sa.gov.au
Information for Substitute Decision-Makers

☐ Read these instructions before you agree to be appointed as a SDM.
☐ Ensure you understand what types of decisions you will be able to make and how the person wants you to make decisions for them.
☐ Keep a certified copy of the person’s ACD form where you can easily find it.
☐ Keep a copy of this Information for Substitute Decision-Makers.
☐ Keep a copy of the Decision-making Pathway (see page 62).
☐ Have regular discussions with the person in case things change for them.

It is important that you discuss with the person who has appointed you:
• what they think is important to them about their future health and life
• their health care preferences and
• what they want you to consider or who to talk to when making decisions for them.

It might be helpful if you make your own notes about your discussions with the person such as:
➢ The names and phone numbers of any other SDMs.
➢ The name and phone number of anyone you may need to contact for the person – for example their doctor or children.
➢ Any information the person has not written in their ACD form. There may be topics which the person finds easier to talk to you about instead of writing down.

By signing the ACD form, you are stating that you agree to be the person’s SDM and that you understand your role and responsibilities.

Do not sign the ACD form until you have read: ▼
• This Information for Substitute Decisions-Makers and
• Decision-making Pathway.

If you need help
The Office of the Public Advocate can give advice to you about your role and help solve problems. See page 58 for more information. Additional information can also be found in Fact Sheet #: Helping to solve disagreements or disputes (to be developed).
What is the role of a substitute decision-maker?

You are reading this because someone wants to appoint you to make decisions for them when they are unable to make their own decisions, whether for a short time or permanently.

Making decisions for someone else can be difficult, especially if you are not sure what they would want. Talking to the person about their ACD and their wishes while they are still able to discuss it with you, can help make it easier if, in the future, you are called on to make a decision(s) for the person.

What decisions can you make?

You can make all the decisions the person wanted you to make, but you cannot:

- Make a decision which would be illegal, such as requesting voluntary euthanasia.
- Refuse food and water to be given to them by mouth
- Refuse medicine for pain or distress (for example palliative care).
- Make legal or financial decisions (unless you have also been appointed as a Financial Power of Attorney).

When contacted and asked to make a decision, you must:

- Produce an original or certified copy of the person’s ACD form or advise if it can be accessed in an electronic record.
- Support them to make their own decision if they are able to.
- Only make decisions which you have been appointed to make.
- Comply with any conditions of your appointment written on the ACD form.
- Try and contact any other SDM appointed to make the same type of decision.
- Only make a decision on your own if any other SDM with the same decision-making responsibility as you cannot be contacted, and the decision is urgent.
- Inform any other SDMs of the decisions you make.
- Try and make a decision you believe the person would have made in the same circumstance – see the Decision-making Pathway to help with decision-making.
Decision-making pathway

The decision-making pathway below will help you to make a decision that is more likely to be one the person would be making if they were able to make their own decisions. It is suggested that you read through this pathway and use it as a guide when making decisions for the person.

For all decisions

Work out if you think the person is able to make the decision

- If you are not sure or if it is unclear if the person can make their own decision you can refer to the Fact Sheet #: Can the person make the decision? (to be developed), seek advice from the Office of the Public Advocate or the person’s doctor.
- If you think the person will be able to make the decision after a short time, and the decision is not urgent, wait until they are well enough to make it themselves.

Allow, support or assist the person to make the decision if they are able.

- Support the person to make the decision if they can – See Fact Sheet #: Assisting someone to make their own decisions (to be developed).
- Even if the person cannot make the decision, if they are awake, try to determine what their current wishes are.

Health care decisions

Step 1: Written or spoken wishes of the person

- Read the ACD to see if the person wrote down any preferred outcomes of care, health care instructions or refusals of health care that are relevant to the decision being made.
- Have you had any discussions with the person that could help you?
- Have they ever expressed relevant views to you or others?
- Remember, if the person has clearly refused health care and intended the refusal to apply to the current situation, you must respect their wishes and say no to the health care.
Step 2: What is important to the person?

- Will the information in Part 3 of the ACD help you make a decision?
- Consider their cultural, spiritual and religious preferences.
- If there are no written directions in the ACD that apply to the situation, consider how the person lived their life.
- Talk with family members and other health practitioners if this is what the person would have done when they were able to make their own decisions.
- How did the person make decisions in the past?
- Consider the likely outcomes of health care and whether the person would want or tolerate these outcomes. You should refuse health care that is likely to result in outcomes that the person wanted to avoid.

Step 3: Making a health decision

- Listen carefully to the advice of health practitioners and ask questions about their health care options and likely outcomes (Fact Sheet #: Questions to ask your doctor – to be developed).
- If relevant, follow the person’s written or spoken wishes or instructions.
- Try and make the decision that the person would make if they had the same information and advice that you have.
- Where there are several options the person would accept, choose the one that gives them the most independence but still provides good care and maximises their health and well-being (as described by them).
- If you cannot work out what the person would have decided, make the decision that you believe is best for them.

Living arrangements and other personal decisions

Step 1: Written or spoken wishes of the person – What is important to them?

- Consider the person’s ACD and any written preferences
- Consider the persons cultural, spiritual and religious wishes or instructions.

Step 2: Making a residential or personal decision

- If possible follow the person’s ACD.
- If there are no written directions in the ACD that apply to the situation, think about what is important to the person (Part 3 of the ACD)
- Talk with family members and others if this is what the person would have done
- How did the person make decisions in the past?
- Consider costs linked to the decisions. Do you need to talk to the person’s financial attorney before a decision is made?
- Where there are several options the person would accept, choose the one that gives them the most independence but still provides good care and maximises their health and well-being (as described by them).
- If you cannot work out what the person would have decided, you must make the decision that you believe is the best one for them personally.
You have been asked to witness someone’s ACD.

- Read this information before witnessing an ACD.
- Check that you fit one of the witness categories (page # to be developed).
- You must be independent of the person you are witnessing for, and cannot be:
  - a beneficiary in the person’s will – for example a family member, or
  - appointed as the person’s SDM or
  - the person’s health practitioner or someone paid to care for the person. **If there is a chance you will be the person’s health practitioner in the future you should not witness their ACD.**

- The **Guideline for Witnesses** (to be available online) provides further advice about witnessing an ACD and includes advice about declining to witness, protections and penalties for witnesses and who you should report any concerns to.
- It is your choice whether you witness a person’s ACD.
- To be legal, an ACD must be completed on the official ACD form – note that it may be completed in hand writing or electronic text.
- Do not witness the ACD form until it has been completed – this includes any SDM signatures. **The person must sign in front of you.**
- You can certify multiple copies at the same time as you witness the person’s original ACD form.
- If you think the person is not competent to complete an ACD, you can request they provide medical documentation which states that they are.

The Witness Checklist on page 65 gives you guidance about what questions you should ask the person to satisfy your obligations as a witness.
Checklist for witnesses

- Verify the name and signature of the person from formal identification documents such as a passport or driver's licence or concession card. If these are unavailable, cards or documents with the person's name, address and signature are acceptable.

- Speak with the person alone so you can assess if they are voluntarily giving the ACD and to limit the possibility of coercion by others.

- Assess whether the person is competent to sign a legal document. A person is competent if they:
  - can understand the nature and effect of the ACD (e.g., what it is, what it will be used for and when it applies) and
  - are freely and voluntarily deciding to complete an ACD and
  - can communicate their decision to complete an ACD in some way.

- Explain to the person:
  - that their ACD will be used in the future if they are not able to make a decision themselves
  - that they do not have to appoint a SDM and that their person responsible could be contacted for health care decisions if they don't appoint anyone
  - they can revoke the ACD at any time while they are still competent (that is they understand the effects of revoking their ACD and do so of their own free will).

- Following the explanation ask the person questions such as:
  - What is your understanding of an ACD? Why have you decided to complete one?
  - Have you read the Kit which comes with the ACD form? What did you find most helpful in it? Why?
  - Have you decided on SDMs. Why did you choose them?
  - If you haven't appointed any SDMs do you know who will make decisions you for when you cannot?
  - When will your ACD be used? What sorts of decisions will it cover?

- If you are satisfied with the above, ask the person to sign the document in front of you.

- Fill in Part 7 of the ACD. Record your name, occupation and contact details and then sign the form.

- Both you and the person must initial each page of the ACD.
Certifying copies

You can certify multiple copies of the person’s original ACD form at the same time that you witness it.

☐ Before certifying an ACD, check that the copy to be certified is an identical copy of the original.

☐ When certifying, you will need to fill in the witness certification panel on the front of the person’s ACD form with a certification statement. You may want to use this suggested wording:

“I, (insert your name), (occupation) certify this and the following … pages to be a true copy of the original as sighted by me”

☐ Sign your name to complete the certification statement.
Information for Interpreters

You are reading this because you have been asked to help someone complete an Advance Care Directive and English is their second language.

The person may have already completed an Advance Care Directive in their own language. If they have, you will need to get another blank Advance Care Directive form (available on the website) and translate their words into English on the new form.

The official copy of the person’s Advance Care Directive must be in English so others, especially those providing health care, can read it.

Work through the Advance Care Directive Kit with the person you are interpreting for.

As the interpreter, you must fill in Part 7b of the Advance Care Directive form.

Important
By signing your name you are certifying that:

- you believe the person you are interpreting for understands what an Advance Care Directive is and what it will be used for in the future and
- that your translation/what you have written on the Advance Care Directive form accurately states the person’s information, wishes and instructions in English.

There are penalties for writing false or misleading statements on an Advance Care Directive or forcing someone to write information on their Advance Care Directive which they do not want to write.

You need to explain to the person that they need to sign their Advance Care Directive in front of an independent witness.

If you are independent of the person:

- not a beneficiary in their Will
- not appointed as their SDM and
- not the person’s health practitioner or paid carer,

you may also be able to witness their Advance Care Directive, provided that your profession is listed in the categories of witness section on page #.
Consultation Draft Do-it-Yourself Advance Care Directives Kit feedback form

I am a (please tick which applies to you):

- [ ] Consumer
- [ ] Consumer organisation
- [ ] Health/aged care professional
- [ ] Organisation representing health /aged care professionals
- [ ] Service provider
- [ ] Lawyer
- [ ] Organisation representing lawyers
- [ ] Other

Please feel free to answer any or all the following questions about the DIY Kit:

1. Do you think the information in the DIY Kit is easy to understand?

2. Do you think the Step by Step Guide (pages 10-38) is easy to follow and helped you to fill in the ACD form?

3. Is the Advance Care Directive form easy to fill out (page 40)

4. The Kit contains examples of statements you could include in your Advance Care Directive. Are these helpful?
5. Are there any other example statements you would like to see included in the Kit?


6. Is there any other information you might need to assist you write an Advance Care Directive?


7. Do you have any other comments?


Next steps

Following this consultation process, the draft DIY Kit will be revised based on your feedback. An online version of the DIY Kit will be developed and will be available to be completed on the new ACD web site. Extra information, fact sheets as well as resources for consumers and professionals will be available on the web site.

1. Are you interested in testing the online DIY Kit or providing feedback about the new draft web site once it is ready?
   - Yes  □ No   Comments..............................................................................

2. Do you have any ideas for promoting the new ACD in the community or among health, aged care, disability and community care workers?
   - Yes  □ No   Comments..............................................................................

3. Would you like to help promote the new Advance Care Directive?
   - Yes  □ No   Comments..............................................................................

If you have said yes to any of the three questions above please provide your contact details.

First name:...........................................  Last name: ...........................................

Contact phone number:............................  Email: ..............................................

I would like my submission to be kept confidential   □ Yes  □ No
For more information:

Advance Care Directives
Policy and Legislation Unit
Department for Health and Ageing
PO Box 287, Rundle Mall
Adelaide SA 5000
Telephone: +61 8226 6717
Email: policy&legislation@health.sa.gov.au