

Now you are a Substitute Decision-Maker

Now you are a substitute decision-maker

This manual is to support substitute decision-makers appointed under Advance Care Directives, in South Australia.

Being a substitute decision-maker (SDM) can be both rewarding and challenging. Making decisions for another person who is not able to make their own decisions places a lot of responsibility on your shoulders. It will not always be easy. However, the fact that you have been appointed shows that you are trusted to make those decisions based on your special knowledge of the person that you will be substitute decision-maker for.

One of the challenges for all substitute decision-makers is the need to put aside your own values and views about life, and make decisions that shape the life of the person you are substitute decision-maker for in ways they would want.

In many situations, you can support someone who needs help to make a decision by encouraging them to express their wishes and preferences.

Substitute decision-makers must use these views, wherever possible and practical, to guide their decisions. Substitute decision-makers also need to consider the person's rights and freedoms. In situations where there are no specific instructions or expressed views, the care of the person and the protection of their interests is also important.

It is this balancing act that you will probably spend the most time thinking about in your role as a substitute decision-maker.

Now you are a substitute decision-maker includes information and guidelines designed to help you in your role. We hope you find it useful. Your feedback will be helpful in the design of future updates to the manual.

We'd like to acknowledge Office of the Public Advocate staff and the Office for Ageing Well/SA Health for their dedication in preparing and reviewing this manual.

We wish you well on your journey together with the person who has appointed you as their substitute decision-maker.

Introduction

An Advance Care Directive is a legal document. It allows the person who makes it to give directions about their future health care, end of life, preferred living arrangements and other personal matters.

When someone makes an Advance Care Directive (or ACD), they may also choose a person they trust to make decisions for them if they are unable to do so themselves. If you are chosen to do this, you are called a substitute decision-maker (or SDM). This guide was written to support and inform you to understand your role and responsibilities.

Although it is written with substitute decision-makers in mind, this guide may also help people who are thinking about making an Advance Care Directive to choose substitute decision-makers willing and able to take on this role. In addition,

carers, family members and professionals who support substitute decision-makers may find this guide helpful.

Your role as a substitute decision-maker can be both rewarding and challenging. Making decisions on behalf of another person is an important responsibility and position of trust. You are a volunteer who must set aside your own beliefs, values and desires and make the decisions that the person would have made for themselves if they were able. Making decisions from the other person's perspective can be a challenging part of the role, and this guide aims to help with this.

We would like to thank every community member, stakeholder and service provider who contributed to the preparation of this guide. Your contributions, reflections and experiences have been essential.

Using this guide

This guide provides information about your role and responsibilities as a substitute decision-maker. It does not use jargon, but for more information about words that are in bold, please refer to the "Glossary of terms" on page 42.

This guide will refer to the person who has completed their Advance Care Directive and appointed their substitute decision-maker(s) as the 'Appointer'.

The *Advance Care Directives Act 2013* and Section 3 of this guide provide more information about Advance Care Directives. The *Advance Care Directives Act 2013* will be referred to as 'the Act'.

This guide will also use the term health practitioner to describe the health professional or doctor providing health care. This term is used because it comes from the Act.

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Section 1: Being chosen as a substitute decision-maker

The substitute decision-maker is a trusted role

Being chosen as a substitute decision-maker means that the Appointer trusts you to make decisions for them, if they are no longer able to make decisions for themselves. Your role is to uphold the Appointer's wishes and rights.

When an Appointer makes their Advance Care Directive, they can choose to list one or more people as their substitute decision-maker(s). Later, if the Appointer is unwell or injured and is unable to make a particular decision on their own, their substitute decision-maker can make the decision for them.

As substitute decision-maker, you can make decisions about health care (including end-of-life decisions), living arrangements and other personal affairs. Legally, decisions made by a substitute decision-maker have the same weight as if the Appointer were making the decisions for themselves.

When an Advance Care Directive is made, and the Appointer has the ability to communicate what they want, it is important for you to make sure you understand the Appointer's wishes. When you are appointed, you should ask your Appointer about their wishes, values, beliefs and other

lifestyle and health care matters that are important to them.

The *Advance Care Directives Act 2013* says that Appointers must be allowed to make their own decisions about their health, accommodation and personal affairs for as long as possible. The Appointer should also be as involved as possible in decisions about their lives. Even if Appointers are not able to make some decisions, they may still be able to make others by themselves or with some support.

Sometimes, doctors or geriatricians carry out tests to try and work out how much help an Appointer may need with their decision-making. However, this is not a requirement. A substitute decision-maker can still help an Appointer, even if there has been no formal assessment of the Appointer's decision-making capacity. You should discuss each decision you make with the Appointer; the guiding principle is that the Appointer should be involved as much as possible in making the decision themselves.

The Appointer may not need help with some decisions, such as what they like to eat or who they would like to spend time with. They may only need support to make some decisions, such as what arrangements might be made for assistance and services in their home.



There may also be decisions that you will need to make for the Appointer, such as complex health care decisions. This is called 'decision-specific' decision-making capacity.

Decision-making capacity is discussed in more detail on page 8 of this guide.

You can also download and print fact sheets from www.sahealth.sa.gov.au and www.opa.sa.gov.au – search for 'decision-making capacity'.

When making a decision, you should make the decision the Appointer would have made, if they were still able to make it themselves.

If the Appointer has outlined medical treatment that they do not want to receive or health outcomes that they want to avoid, you must follow these instructions. These instructions are called **binding refusals**[#].

Considerations for appointing a substitute decision-maker

A person completing an Advance Care Directive can ask a friend or family member to be their substitute decision-maker. If you are chosen, you must agree to be appointed and sign the Advance Care Directive before the document is witnessed. Signing the Advance Care Directive shows that you have agreed to be appointed, understand the role and responsibilities and are willing to uphold the Appointer's wishes and values if possible.*

Good planning and communication between the Appointer and the substitute decision-maker are very important. If both people are able to discuss the Appointer's wishes before the Advance Care Directive is made, the decision-making process is easier for both the substitute decision-maker and the Appointer.

[#]These do not apply in the case of suicide or self-harm.
^{*}The Act uses the phrase 'as far as is reasonably practicable'.

A person appointed in the substitute decision-maker role must be someone the Appointer can trust and also have the empathy and confidence to make the decisions the Appointer has requested. At times, there can be pressure or questions from family, friends or health practitioners. The substitute decision-maker role is also unpaid and can be time consuming.

Substitute decision-makers must be over 18 years old and willing to commit to the role. You must ensure you are available and contactable when decisions need to be made. You must be clear and assertive and be a good advocate for your Appointer.

Some people cannot be appointed as a substitute decision-maker, including:

- > a person who has impaired decision-making capacity
- > a health practitioner responsible for the health care of the Appointer (for example, the Appointer's regular doctor)
- > a paid carer of the Appointer, such as a service provider (this is not a family carer).

Case study

After learning she had a life-limiting illness, Josie decided to complete an Advance Care Directive. Josie had a partner, but it was a new relationship. Josie also knew her dad would find it hard to make decisions about the health care that Josie wanted—not what Josie's Dad wanted, or thought was best for Josie.

Therefore, Josie asked her aunty to be her substitute decision-maker. Josie was confident that her aunty would represent her wishes, stay true to Josie's preferences and make decisions confidently on Josie's behalf. Josie trusted her aunty, who was very honoured to take on the substitute decision-maker role for Josie.

Types of decisions a substitute decision-maker can make

- > Accommodation
 - short- or long-term living arrangements
 - respite
- > Health care
 - medication, transplants, treatment for illness and surgery
 - treatment for mental health
 - dental treatment
 - physiotherapy, allied health care and rehabilitation

- vaccinations
- life-sustaining treatment, life support and resuscitation
- artificial nutrition and hydration
- pain management and medication
- > End-of-life treatment and palliative care
- > Personal affairs
 - visitors, ongoing relationships and contact with people important to the Appointer
 - grooming
 - social activities
 - in-home support services
- > Spiritual, cultural and religious matters
 - end-of-life practices
 - attendance at church, rituals or ceremonies.

What a substitute decision-maker cannot do

- > refuse for pain relief medication to be provided to the Appointer
- > refuse for food or water to be provided to the Appointer
- > make a decision that would be against the law in South Australia, such as obtaining or providing illegal substances
- > seek sterilisation or termination of pregnancy

- > make decisions that involve financial or legal matters (unless the substitute decision-maker is also appointed as the attorney under an **Enduring Power of Attorney**)
- > consent to Voluntary Assisted Dying on behalf of the Appointer.

As a substitute decision-maker, you do not have to provide day-to-day care for the Appointer. You also do not have to help with paying bills, taking the Appointer to medical appointments or maintaining the Appointer's house. A substitute decision-maker may also be a family carer, cleaner or attorney (appointed under a Power of Attorney), but these roles are separate from the substitute decision-maker role.

You should take care that you assist with decision-making only as you are needed to make sure that the Appointer's wishes are upheld. Your role is not to control the daily life of the Appointer.

Section 2: Role of a substitute decision-maker

When the substitute decision-maker role begins: Decision-specific capacity

As a substitute decision-maker, you can help the Appointer to make decisions if they are unable to manage parts of the decision-making process. The Act calls this **impaired decision-making capacity**. Determining whether the Appointer is able to make a particular decision or have decision-making capacity should be a process of conversation and collaboration with the Appointer.

Everyone in our community is presumed to have the capacity to make their own decisions, unless there is evidence that they do not. You may need to help if the Appointer is not able to manage parts of the following:

- > understanding some or all of the information that is relevant to a decision
- > understanding the consequences of a decision
- > remembering the relevant information, even for a short time
- > using this information to make a decision
- > communicating their decision to others in some way.

The Appointer may still have the capacity to make a particular decision, even if the following applies:

- > They are not able to understand trivial or technical information
- > They can only remember information for long enough to use the information to work out a decision
- > They make a decision that results in a negative outcome
- > Their ability to make decisions changes between 'full' decision-making capacity and 'impaired' decision-making capacity.

It can sometimes be challenging to work out who makes what decision. The important thing to remember is that the Appointer should be encouraged and supported to be as involved in the decision-making process as they are able to be. You should be involved only to the extent that you are needed for a particular decision.

Sometimes, a **general practitioner** or a **geriatrician** can complete a formal assessment of an Appointer's decision-making capacity. This can help everyone involved to understand what kind of assistance the Appointer needs.

Case study

Helen made her Advance Care Directive before her ability to make decisions for herself started to decline. She had become very forgetful and needed lots of help with daily-living activities, such as dressing herself and preparing simple meals.

Recently, when she needed hip surgery, her husband and substitute decision-maker, Harold, was called on to discuss the surgery with Helen and give consent, as the decision was too complex for Helen to make alone. It was Harold's responsibility as substitute decision-maker to uphold her wishes when making this decision.

Although Helen was no longer able to use the phone without help, she still told Harold every day that she would like to call her daughter (Harold's step-daughter) in Tasmania. Helen was able to make this decision to maintain contact with her beloved daughter, and it was Harold's responsibility as substitute decision-maker to support Helen by facilitating the phone calls.

When someone is able to make certain decisions (such as Helen's decision to stay in contact with her daughter interstate) but is unable to make others (such as complex health care decisions), this is an example of decision-specific capacity.

Visit www.sahealth.sa.gov.au and search 'impaired decision-making' to download and print a fact sheet.



The decision-making process

Principles of the Act

It is a human right to make our own decisions. If a person's right to make some or all of their own decisions is not able to be upheld, and you (as the appointed substitute decision-maker) need to make a decision, it is important that you understand the law. A substitute decision-maker must make decisions based on the **Principles** of the Act.

The Act (sections 10 and 35) states that as a substitute decision-maker, you must, as much as you possibly can:

- > uphold the values, wishes and instructions the Appointer has written in their Advance Care Directive
- > avoid any outcomes, treatments or interventions that the Appointer wanted to avoid
- > ask the Appointer about their wishes and needs and consider these in your decision-making
- > make the decisions you believe the Appointer would have made under the circumstances
- > not restrict the basic rights and freedoms of the Appointer

- > consider the Appointer's past and present wishes, along with any values they have displayed or expressed in their life
- > give priority to the Appointer's wishes if there is a disagreement about a decision
- > make decisions that fit well with the proper care of the Appointer and protection of the Appointer's rights and interests, if there are no specific instructions or expressed views.

The Principles of the Act outline how to make sure that substitute decisions and their outcomes reflect what the Appointer would have chosen for themselves in the same situation.

The Principles of the Act also release you from the burden of making the 'best' decisions for the Appointer. The focus should be on making decisions that reflect the Appointer's wishes, rather than your own wishes, values or beliefs.

Preserving the Appointer's confidentiality is also important. You should be mindful of what information you share and with whom. An Advance Care Directive may include instructions about information sharing, and it can be helpful to talk about this with the Appointer.

You should let your Appointer know when you have been asked to make

a decision, so you can talk through the decision together. Even if the Appointer has limited decision-making capacity, you should still talk with them and involve them in the decision as much as possible. This promotes the Appointer's right to participate in decisions that affect their life. When substitute decision-makers make decisions alongside Appointers in this way, this is called a **supported decision-making approach**.

Depending on an Appointer's capacity to be involved in a particular decision, you may move freely between supported decision-making (which includes the Appointer in the decision-making process) and substitute decision-making (where the Appointer is not able to be directly involved due to impaired decision-making capacity).

To help make informed and appropriate decisions, you can also ask for advice from others, including professionals and experts.

The intention of the *Advance Care Directives Act 2013* and its Principles is that substitute decision-makers become involved only as they are needed to make sure that the Appointer's wishes are upheld. Their role is not to control the daily life of the Appointer.

Cultural, spiritual and diversity considerations

Before committing to the substitute decision-maker role, you should talk with your Appointer about any important cultural, spiritual or personal preferences.

The following questions can help you check that you understand these issues while the Appointer has decision-making capacity:

- > Who is important in the decision-making process?
 - Perhaps there is an Elder, religious leader, neighbour or family member (including **family of choice**)?
- > Are there cultural beliefs about death, pain, organ donation and/or medication that might be relevant to any decisions?
- > Has the Appointer had previous experiences with health practitioners that have not been positive or have affected levels of trust towards professionals and services?
- > Are there practices or rituals that might be important?
- > Are there family members that the Appointer does not want to have involved in their care, treatment, decisions or life?



Notes about these conversations can be stored with the Appointer's Advance Care Directive for future reference.

Languages other than English

An Advance Care Directive must be completed in English. If an Appointer does not speak English, they can use an interpreter to write their Advance Care Directive. The interpreter must complete the required sections of an Advance Care Directive form to confirm that the Appointer understands everything in the form.

To ensure they understand all the information related to a decision, substitute decision-makers who do not speak English can also use interpreters.

Interpreters:

- > must be at least 18 years of age
- > must have decision-making capacity in relation to the decision they are interpreting
- > may also act as a witness to the document
- > must not be listed as a substitute decision-maker for the Appointer
- > must not have an interest in the Appointer's estate
- > must not be the Appointer's doctor or someone else in charge of their health care
- > must not hold a position of authority at a hospital or facility where the Appointer lives

See Resources on page 40 for more information about how to access an interpreter.

When more than one substitute decision-maker is appointed

An Appointer can choose more than one substitute decision-maker. If there are two or more substitute decision-makers, they can be appointed 'separately' or 'together' to make decisions.

The Appointer may:

- > appoint their substitute decision-makers in order of priority for when a decision needs to be made.

- > say who they want to make particular decisions
- > appoint a substitute decision-maker who can only make decisions if another substitute decision-maker is not available.

An Appointer may also write down that they prefer certain information is shared or kept private, or that they would like particular people to be involved in specific decisions.

SEPARATELY	TOGETHER	SEPARATELY AND TOGETHER
<p>If the Appointer writes in their Advance Care Directive that their substitute decision-makers are appointed separately, it means they can make decisions together or alone. If one substitute decision-maker makes a decision alone, they must advise the other decision-maker(s) of the decision.</p>	<p>If the Appointer writes in their Advance Care Directive that their substitute decision-makers are appointed together, it means they must make decisions together.</p>	<p>If the Appointer does not say whether they are appointed 'separately' or 'together' then, by default, the substitute decision-makers are appointed separately and together. It means they can make decisions separately or together.</p>

The following page has an example of making decisions separately and together.

Case study

When Edith made her Advance Care Directive, she did not specify whether her daughters should make decisions separately or together. Therefore, Edith's two daughters default to making decisions 'separately and together'.

When day-to-day decisions need to be made, like buying new clothes for mum, or booking an outing on the community bus, one daughter will usually help mum make this decision, and then let the other daughter know.

When more significant decisions are needed, such as giving consent for mum's dental treatment, or deciding whether to move mum to a different room in her aged care facility, Edith's daughters discuss these things together and make sure they agree before making a decision.

Talking through important decisions helps to reduce the chance of conflict between the two decision-makers, even if they think they will probably agree on the decision. Both daughters feel that they are trusted to make day-to-day decisions, and they keep the lines of communication open so that they can address any concerns before they make any big decisions.

Steps for decision-making

The decision-making process can be challenging and even confusing. As a substitute decision-maker, you must consider the things on the list when making a decision. It will help you prioritise the information you have.

- 1 Binding provisions/refusals
- 2 Expressed wishes (anything within the Advance Care Directive)
- 3 Outcomes the Appointer wishes to avoid
- 4 Known or implied preferences, wishes, views, beliefs, values, lifestyle
- 5 Short-term and long-term risks and consequences

The Appointer's wishes are always the most important consideration. You should try to become familiar with these wishes while you are able to communicate with the Appointer and the Appointer has the capacity to express their wishes.

See page 23 for conversation starters to help explore these questions together.



Binding refusals

If an Appointer has expressed, written or implied in their Advance Care Directive that they do not want a particular treatment or health care, this is called a binding provision. If someone refuses a particular health care, this is binding, which means the substitute decision-maker and health practitioners must follow the refusal. All other expressed wishes are non-binding but must guide decision-making.

Case study

Graham is a retired veteran, who made his Advance Care Directive in his seventies when he realised that his health was deteriorating. His best mate since the war, Charlie, had always been there for him. Even though Graham loved and trusted his brother and sister (his only close relatives), he knew that Charlie in particular would be strong enough to make the decisions he wanted. Graham appointed Charlie as his substitute decision-maker. He also told all of his family and friends about his Advance Care Directive and that he would love for them to uphold his wishes.

Years later, when Graham was admitted to hospital after a heart attack, it was confirmed that he had advanced dementia. The doctors contacted his family to give their consent for life-saving heart by-pass surgery. Graham's brother mentioned the Advance Care Directive and told the doctors that Graham's substitute decision-maker, Charlie, would need to give consent.

Charlie rushed to the hospital and discussed Graham's prognosis and treatment options with the health care team and Graham's family. He knew what he needed to do—Graham's Advance Care Directive clearly stated that if Graham was unable to recognise his family and friends, he did not want any life-saving surgery. Even though his family was sad, they all agreed that they would uphold his wishes, and Charlie gave consent for the health care team to provide comfort care to Graham.

Proper care and protection

No documented expressed wishes

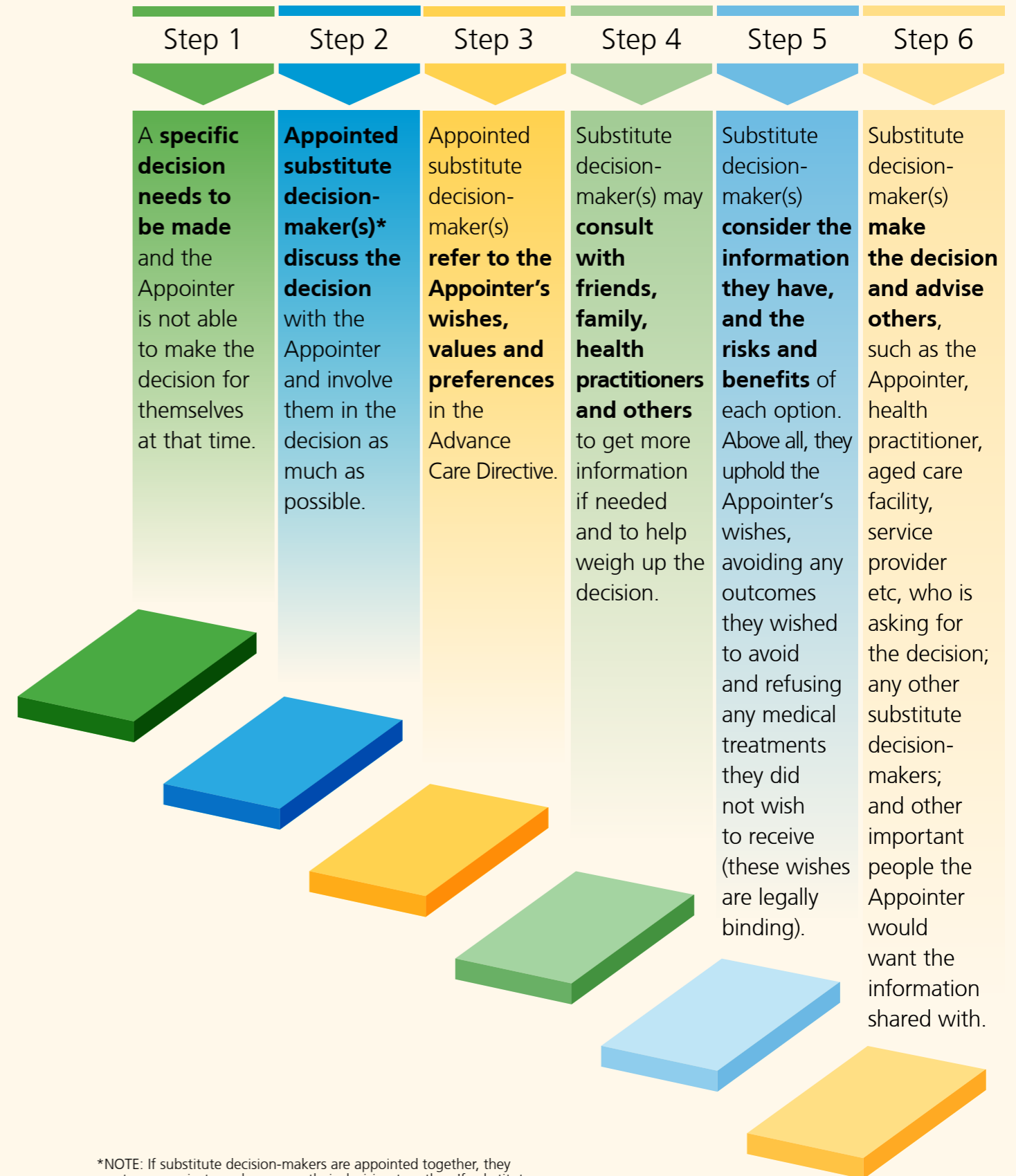
If the substitute decision-maker does not have the information that they need or does not know what the Appointer's preferences would have been in the same situation, making a decision can be very difficult. This is even more of a challenge if there are time pressures.

You must review the Advance Care Directive and you may also consult health practitioners, family and friends to ensure your decision-making is well informed. However, if such people do not know what decisions the Appointer would have made or there are no specific instructions or expressed wishes in the Advance Care Directive, you must do as follows:

- > make a decision consistent with the proper care of the Appointer
- > protect the Appointer's interests
- > avoid restricting the Appointer's basic rights and freedoms as far as is reasonably possible.

The decision-making process on the next page shows what this might look like if there is enough time.

Decision-making process: doing what the Appointer would have wanted



*NOTE: If substitute decision-makers are appointed together, they must communicate and agree on their decision together. If substitute decision-makers are appointed separately, or separately and together, one decision-maker could make a decision independently and then advise the other substitute decision-maker(s) of their decision.

Information the substitute decision-maker must have access to

When there is a decision to be made, you must be given all of the information you need. To make an informed decision, a substitute decision-maker has the authority to ask for any information and documents (related to the accommodation, health or lifestyle decision) that would normally be given to the Appointer.

If there is a health care decision to be made, this would include information from health practitioners about any treatment options, risks, benefits and expected outcomes, including outcomes from not having the treatment.

If there is an accommodation decision to be made, this would include all details about accommodation features, locations and services. In addition, you may need to work with the Appointer's appointed financial decision-maker (called an **'attorney'**) to ensure that the Appointer's financial situation is also considered.

It is a good idea for substitute decision-makers to keep records of any information they are given to use in their decision-making.

Substitute decision-makers are accountable for their decisions

Substitute decision-makers are accountable to the Appointer, any other appointed substitute decision-makers and the South Australian Civil and Administrative Tribunal (SACAT). Anyone who has an interest in the life of the Appointer can make an application to the South Australian Civil and Administrative Tribunal if they have concerns about decisions or decision-makers.

If more than one substitute decision-maker is appointed and the Advance Care Directive does not provide any specific conditions, they can make decisions together or separately.

If you are one of several substitute decision-makers and you are allowed to make decisions separately (or 'severally'), you must do your best to let the other decision-maker(s) know about any decision you make.

Documentation and record-keeping

Substitute decision-makers must have a certified copy of the Advance Care Directive that appoints them. You must show this copy to anyone who needs to see it when you make a decision for the Appointer. You can show a paper or digital copy of the document.

Certified copies of Advance Care Directives should also be given to health practitioners, health services and accommodation providers (for example, aged care facilities). If a digital copy is stored in the Appointer's hospital records, health practitioners can use this to check who has decision-making authority. There is no central register in South Australia that keeps records or copies of Advance Care Directives, but a copy can be saved in the Appointer's online health record, called My Health Record – www.myhealthrecord.gov.au

When the Appointer makes their Advance Care Directive, it is a good idea for them to let family and friends know who they trust to help them with decision-making and to share their wishes with others. They could also give certified copies to other people who are close to them. This helps family and friends to support substitute decision-makers as they try to uphold the Appointer's wishes. It can also help prevent unnecessary conflict about decisions and decision-makers.



Common myths about the substitute decision-maker role

Below are some examples of common myths and misconceptions around Advance Care Directives and substitute decision-makers.

Myth	Fact
A guardian appointed by the South Australian Civil and Administrative Tribunal (SACAT) has more authority than a substitute decision-maker appointed under an Advance Care Directive.	A guardian and a substitute decision-maker have the same authority. If someone has made an Advance Care Directive and appointed a substitute decision-maker, they do not need a guardian/Guardianship Order from the South Australian Civil and Administrative Tribunal for any decisions.
A family member can add wishes and requests to an Advance Care Directive if the family member believes the Appointer has forgotten to include something.	No person can list wishes in an Advance Care Directive other than the Appointer at the time of making the document. Once the document is signed and witnessed, it cannot be changed. If the Appointer wishes to make changes, and they have the legal capacity to do so, they can make a new Advance Care Directive. Making a new Advance Care Directive makes the old one invalid.
Health practitioners can override an Advance Care Directive and/or a substitute decision-maker.	<p>Health practitioners should honour the Advance Care Directive and, if at all possible, treat the Appointer as they have instructed.</p> <p>A health practitioner cannot give any medical treatment that the Appointer has said they want to avoid, as this is a 'binding refusal'.</p> <p>However, a doctor also cannot be forced to give treatment that the Appointer might request. If the doctor believes that a certain treatment would be futile or would cause harm to the Appointer, they can choose not to give the treatment.</p>

Myth	Fact
If someone has a will and an Enduring Power of Attorney they do not need an Advance Care Directive.	<p>A will contains information that is only relevant after someone has passed away.</p> <p>An Enduring Power of Attorney appoints a person to make financial or legal decisions on someone's behalf if they do not have the decision-making capacity to make financial or legal decisions.</p> <p>An Advance Care Directive is the document that details a person's wishes and appoints a substitute decision-maker to make decisions about the Appointer's accommodation, health care and/or personal affairs if the Appointer is not able to make a particular decision for themselves.</p>
If someone makes a decision for themselves that others think is very risky, or the decision leads to negative outcomes, this means that the person has impaired decision-making capacity.	Every person has the right to take risks that they believe are worthwhile and to make decisions and do things that might end badly. This does not automatically mean that the person does not have decision-making capacity. See 'decision-making capacity' on page 43.
A substitute decision-maker should make decisions that are in the Appointer's 'best interests', regardless of the Appointer's wishes.	The <i>Advance Care Directives Act 2013</i> says that the Appointer's wishes are the highest priority, and any decisions made for them must uphold their rights (i.e. their values, wishes, preferences and freedoms). A substitute decision-maker must make the decision the Appointer would have made for themselves, rather than what they may think is 'best' for the Appointer.

Understanding the difference between 'best interests' and 'upholding rights'

Before taking on the role of a substitute decision-maker, you need to understand that you will not be making decisions for the Appointer based on your own personal needs, wishes or preferences. Substitute decision-makers are also not appointed to make decisions in a person's best interests.

Instead, you must understand the Appointer's history, wishes, requests, values and preferences, to make sure you make the decision(s) the Appointer would have made for themselves if they could have. In the Advance Care Directive, the Appointer should write enough information for you to know exactly how the Appointer wants you to act and which decisions to make.

For example, an Appointer may write in their Advance Care Directive that they would prefer to live at home, with some extra support from a home care provider as the Appointer's care needs increase. This may be seen as unwise, and there may even be some risk to the Appointer in staying at home. Therefore, you may believe that it is in the Appointer's best interests to move to an aged care facility.

Instead of making this decision in the Appointer's 'best interests', you must, as far as possible*, make the decision that the Appointer would make themselves. This includes accepting the level of risk that the Appointer would have felt comfortable with and giving priority to avoiding the outcome that the Appointer would have wanted to avoid (for example, leaving their home).

For more about the decision-making role see Section 4 on page 32 in this guide.

*The Act uses the phrase 'as far as is reasonably practicable'.

Section 3: Advance Care Directives and the role of a substitute decision-maker

Overview of an Advance Care Directive

An Advance Care Directive is a legal document. If a person is over 18 years of age and is legally able to sign documents, they can legally make an Advance Care Directive.

An Advance Care Directive becomes legal once it is signed by the substitute decision-maker (if one is appointed) and the Appointer and is then witnessed. The substitute decision-maker, however, only acts (makes a supported or substitute decision) when the Appointer does not have capacity to make a particular decision for themselves.

An Advance Care Directive:

- > is a legal document that outlines wishes and instructions about the Appointer's health care, accommodation and personal affairs. This may include end-of-life decisions and treatment that the Appointer would like to avoid or refuse
- > includes Enduring Power of Guardianship, Medical Power of Attorney and Anticipatory Direction documents made before 2014

- > may appoint as many substitute decision-makers as the Appointer wishes, to make decisions if the Appointer is unable to make the decisions themselves
- > does not allow anyone to make decisions about the Appointer's finances, property or legal affairs
- > is not a will—a will needs to be completed separately and takes effect only after a person dies.

Case study

Lewis is a 30-year-old single father with two school-aged children. Lewis had a serious car accident and needed to stay in hospital for several weeks. It was a very difficult time for his family. During that time, he was not conscious and not able to make decisions about his own treatment. Lewis and his family, however, were relieved that he had completed his Advance Care Directive several years before. He had chosen his close friend, as well as his father, as joint substitute decision-makers. Both people were able to make decisions together for Lewis during this time, based on the wishes he had written in his Advance Care Directive.

Developing an Advance Care Directive

When completing an Advance Care Directive it is important to know the following:

- > The official South Australian Advance Care Directive form must be used.
- > The form must be signed by the substitute decision-maker(s) first (if one is appointed) and then the Appointer second.
- > The Appointer can list as many substitute decision-makers as they wish.
- > The form must be witnessed and signed by an independent authorised witness. (For more information about authorised witnesses, see the Advance Care Directives Regulations 2014, at www.legislation.sa.gov.au).
- > The witness cannot have an interest in the Appointer's estate.
- > The witness cannot be the Appointer's doctor or someone else in charge of their care.
- > The more details that are included in an Advance Care Directive, the more the substitute decision-maker can know about the Appointer's wishes and how to best uphold them.

Sharing documents and information

There is no register for Advance Care Directives in South Australia, which means the following:

- > Ideally, the Appointer should let their family, friends and health practitioners know about their Advance Care Directive, their wishes and whom they have chosen to make decisions for them if needed.
- > Certified copies of an Advance Care Directive should be given to all substitute decision-makers.
- > A certified copy of the Advance Care Directive should be given to the Appointer's health practitioner and others involved in the Appointer's care.
- > Certified copies of the Advance Care Directive should be kept somewhere easy to find (e.g., on a fridge, in a glovebox and/or in a purse/wallet).
- > When they need to make decisions for the Appointer, substitute decision-makers must show a certified paper or digital copy of the Advance Care Directive to others.

Conversation starters to understand someone's wishes

Talk to the Appointer to find out their views on their accommodation, health care, end-of-life decisions, values, wishes, preferences and what is important to them about their lifestyle.

Ideally, the Appointer and their substitute decision-maker(s) should discuss these topics before the Advance Care Directive is signed—just in case there are differences or issues that cannot be resolved.

Through conversation, you may find you hold different beliefs to the Appointer. If you have doubts about taking on the role of upholding the Appointer's wishes, you must tell them you feel this way. You don't have to accept being appointed as a substitute decision-maker.

These conversations should continue after the document is signed, especially while the Appointer has full decision-making capacity. You should revisit them if circumstances change a lot—for example, if the Appointer is diagnosed with a serious illness. Over time, these conversations can continue to deepen your understanding about the Appointer's values, preferences and beliefs.

These pages include some questions you and your Appointer can discuss. Tear out the page and take it with you, so you can refer to it during your conversation.

Lifestyle

If you were going to have a great day, what would you do?

What do you cherish the most about your life?

What is your favourite daily activity?



Who in your life is most important to you?

What do you value: a longer life with less quality or quality of life over quantity?

What does quality of life mean to you? What is most important to you?

What special events, ceremonies or rituals would you want to continue? What special things would you not want to miss?

Whom would you like to stay in contact with?

What is on your bucket list?

Accommodation

Where is home to you? What does home mean to you?

If you couldn't live at home, what would your second preference be? What is your next best option?



What would you like me to consider if I have to make a decision about where you live?

Do you have a pet or companion animal that is important to you?

Health

What do you think about the idea of organ donation? Have you ever discussed this with your family or friends?

Can I share information with your family or friends about the decisions I make? Whom are you comfortable for me to share with?

Is there anything you would like me to keep private?

Towards the end of your life, do you have specific preferences or wishes about treatment or health care?

What outcomes do you want to avoid?



Do you have specific wishes that apply if you become terminally ill or not able to recognise family and friends?

Whom would you like to visit you? Is there anyone you would not like to visit you?

How do you feel about the use of pain medication? What about pain relief at the end of your life?

How do you feel about Voluntary Assisted Dying, and in what circumstances would this be acceptable (if at all)?

Do you have any spiritual, religious or cultural beliefs you would like me to consider when I make decisions for you?

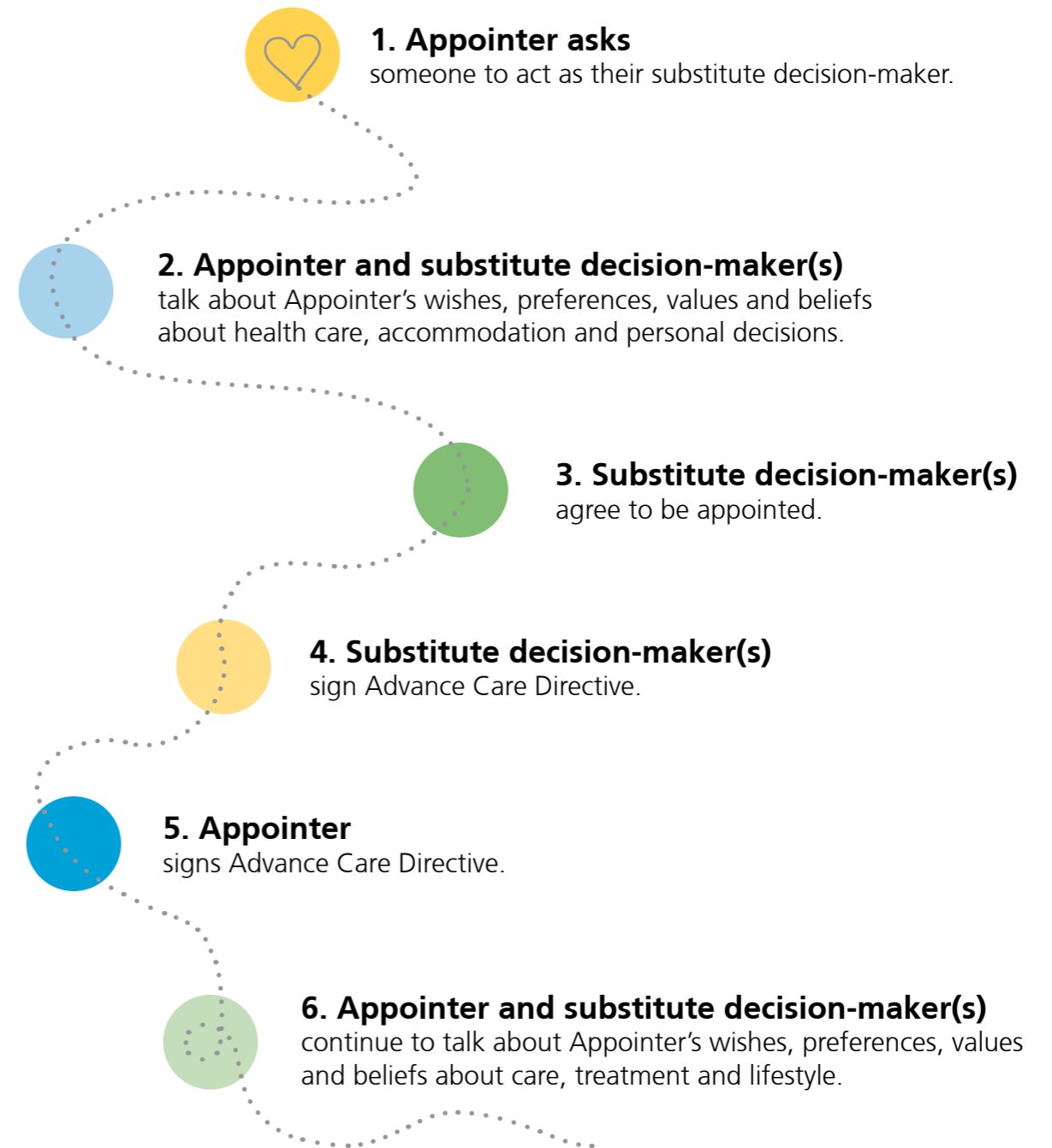
Do your beliefs affect how you feel about medication, pain or the end of your life?

Have you ever had any treatment or medication that you would not want again?

Who would you like me to share your wishes with? Is there anyone you would not like me to share your wishes with?

Signing and witnessing an Advance Care Directive

When an Appointer is making an Advance Care Directive, there are a number of important steps to follow in order for the document to be properly signed and witnessed. This chart sets out these steps.



Changing an Advance Care Directive

Once an Advance Care Directive document is made, signed and witnessed, it cannot be edited or changed in any way, even by the Appointer.

If the Appointer decides that they want to change something, they need to make a new Advance Care Directive and have it signed and witnessed. This new document would then override the previous one. Of course, the Appointer must have the legal capacity to make a new Advance Care Directive.

If the Appointer is not legally able to make a new document, then their family, friends and care providers

should work together to uphold their wishes as stated in their Advance Care Directive. If there is conflict about a decision or a decision-maker, the Office of the Public Advocate Dispute Resolution Service can assist with this.

If the Appointer is not legally able to make a new document and there is conflict that cannot be resolved, or if the Appointer does not agree with decisions that are being made for them, then someone may need to make an application to the South Australian Civil and Administrative Tribunal for orders to be made. The Tribunal is the only one who can override the Advance Care Directive document.



Advance care planning in other states

This guide is based on the South Australian *Advance Care Directives Act 2013*. Advance care planning is different for different Australian states and is guided by various laws. If you are looking for information about states outside of South Australia, you can find it at www.advancecareplanning.org.au.

An Advance Care Directive made in another state will be honoured in South Australia, as long as the instructions written in the document are legal in South Australia.

Previous advance care planning documents

Enduring Powers of Guardianship, Medical Powers of Attorney and Anticipatory Directions are no longer made in South Australia. They have been replaced by the Advance Care Directive form. However, if the forms mentioned were completed and signed prior to 1 July 2014, they are still valid. These documents are now referred to as Advance Care Directives, and they are treated as if they were made under the current Act.

A substitute decision-maker appointed under a Medical Power of Attorney is only able to make health care decisions, even though the document is treated as an Advance Care Directive.



Section 4: When difficulties arise

Getting more information about difficult decisions

As a substitute decision-maker, you can ask health practitioners and other professionals as many questions as you need to. You should make sure you understand all the different aspects of a decision. This includes asking about and considering the likely outcomes.

The Appointer's family, friends or service providers can also support you to make difficult decisions.

As long as the Appointer is happy for the information to be shared, talking to others, getting their opinions and sharing information about difficult decisions can be helpful. Open communication can help to reduce conflict and also reduce your load.

Even though other input can be helpful, the most important things for you to know are the wishes, values, preferences and binding refusals of the Appointer. Even if health practitioners and the substitute decision-maker disagree with the Appointer's wishes, if it is possible to uphold them, this should be done.

Restrictive practices and the substitute decision-maker role

When someone restricts the rights and freedoms of a person they are caring for or stops them from doing something they want to do (to protect their safety or the safety of others), this is called a **restrictive practice**.

Sometimes a substitute decision-maker will need to make a decision that restricts the rights and freedoms of their Appointer or stops them from doing something they want to do. If an Appointer does not have decision-making capacity, substitute decision-makers can give approval to use restrictive practices in special situations.

Visit our website for more information:
www.opa.sa.gov.au

Restrictive practices include:

- > chemical restraint—medication that changes someone's behaviour (e.g., types of sedation)
- > environmental restraint—restricting someone's access to things (e.g., restricting access to sharp objects by locking drawers)
- > mechanical restraint—a device restricting someone's movement for behavioural purposes (e.g., bed rails to stop them getting out of bed).

You need to understand any risks of the restrictive practice, along with any risks to the Appointer if they are not used. Health practitioners and care staff can give this information. You should feel confident to ask health practitioners and service providers

what other strategies are available and what other strategies have been tried before allowing restraint to be used.

These practices are reviewed regularly by care providers and can only be used in the way that the law describes.

Restrictive practice examples

Millie is 24 years old and lives at home with her dad, Jim, who is also her substitute decision-maker. Millie is constantly looking for cleaning products in the house and is not able to understand the consequences of playing with poisons, so Jim has to always make sure that the products are locked away. This is a restrictive practice (environmental restraint). Jim provides other safe liquids to satisfy her curiosity.

Carol needs help with her decision-making and struggles with her emotions. She often has emotional outbursts and repeatedly bangs her head against the wall, which places her at risk. To keep Carol safe, her substitute decision-maker has authorised Carol to take anti-anxiety medication, even though she has not been given a mental health diagnosis. This is a restrictive practice (chemical restraint).

NOTE: if the Appointer is a National Disability Insurance Scheme (NDIS) participant, the Department of Human Services Restrictive Practice Unit must authorise any restrictive practices. In this case, substitute decision-makers should be consulted, but their consent is not essential. For more details, see the Resources section of this guide.

Dave is a retiree who has moderate dementia. He is not able to respond to his appetite anymore or to regulate his food intake and will often eat compulsively—to the point of being sick. Dave's sister, also his substitute decision-maker, works with the staff at the aged care facility where he lives to make sure that Dave has enough food at mealtimes, as well as snacks. But his supply of food is monitored and limited. This is a restrictive practice (environmental restraint).

NOTE: if the Appointer is a resident of an aged care facility and not an NDIS participant, the substitute decision-maker provides authorisation.

A substitute decision maker cannot authorise physical restrictive practices (or physical restraint) for residents of aged care facilities. Only the South Australian Civil and Administrative Tribunal can authorise this (please see information about Special powers on page 34 of this guide).

For NDIS participants, the Department of Human Services Restrictive Practices Unit authorises physical restrictive practices by an NDIS service provider.



Special powers and the substitute decision-maker role

Sometimes, when an Appointer does not have the capacity to make their own decisions and their health or safety is at risk, a substitute decision-maker might need to make a decision that the Appointer does not agree with. The substitute decision-maker may then need to apply to the South Australian Civil and Administrative Tribunal for **special powers**.

Special powers are also called **Section 32 powers** because they are explained in Section 32 of the *Guardianship and Administration Act 1993*.

Special powers are legal orders that give you (as the substitute decision-maker) more authority due to the Appointer, or someone around them, needing to be kept safe. This allows you to make particular types of decisions that you would not ordinarily be allowed to make.

Special powers can give substitute decision-makers the authority to do the following:

- > say that the Appointer must live in a particular place (even if they don't want to)
- > say that the Appointer is not allowed to leave a particular place

- > say that force can be used, so that medical or dental treatment can be given.

For example, special powers might be needed if the Appointer needs to live in a closed **Memory Support Unit** or if they need dental treatment that they are refusing.

It should be noted that if the Appointer has outlined in their Advance Care Directive medical treatment that they do not want to receive or health outcomes that they want to avoid, you must follow these instructions. These instructions, written down when the Appointer had legal capacity, are called **binding refusals**.

All special powers orders are reviewed regularly by the South Australian Civil and Administrative Tribunal.

Special powers are what is called a 'last resort', which means that they must only be made if there is a risk to someone's health or safety. Other approaches to help or treat a person should be attempted first, and a less restrictive option should be used when possible.

More information about special powers is available at the Office of the Public Advocate website (www.opa.sa.gov.au) and on the South Australian Civil and Administrative Tribunal (SACAT) website (www.sacat.sa.gov.au).

Health care consent where there is no substitute decision-maker

Not every person who makes an Advance Care Directive appoints a substitute decision-maker. Sometimes, an Advance Care Directive only contains an Appointer's instructions and wishes about their accommodation, health care and personal affairs. This is still a valid document.

If a person is not able to make a particular health care decision themselves, their health practitioner must check if the person has made an Advance Care Directive, and in particular, whether they have made any 'binding refusals' of treatment. If one has been appointed, a substitute decision-maker would be the first person asked to give consent for medical treatment/health care. Substitute decision-makers have priority over family, close friends or loved ones.

The Consent to *Medical Treatment and Palliative Care Act 1995* sets out (in order) the people who can consent to or refuse medical treatment and health care if someone is not able to make the decision themselves.

A 'Person Responsible' is the term for those people who are able to



make health care decisions on behalf of someone who is not able to give consent for their own treatment and does not have an Advance Care Directive or has not appointed a substitute decision-maker.

A Person Responsible has legal authority and can provide/refuse consent according to the following legal order:

1. A guardian with health care decision-making powers appointed by the South Australian Civil and Administrative Tribunal
2. A prescribed relative¹ with a close and continuing relationship, who is available and willing to make the decision(s)

3. An adult friend with a close and continuing relationship, who is available and willing to make the decision(s)
4. An adult who is charged with overseeing the ongoing day-to-day supervision, care and well-being of the person and who is available and willing to make the decision(s) (not including chemical restraint).

A frequently asked questions fact sheet about the role of a 'Person Responsible' is available from www.sahealth.sa.gov.au – search for 'consent act changes'.

1. Adult spouse or domestic partner or adult related by blood, marriage or adoption or Aboriginal kinship rules/marriage

Sometimes, in emergency situations, health practitioners may not be able to contact a substitute decision-maker or Person Responsible about medical treatment. The Advance Care Directive may also not be clear or relevant. In these situations, emergency treatment can be given if there is an urgent risk to someone's life or health and a second health practitioner is supportive of the treatment.

Conflict between substitute decision-makers and others

It is important to keep the lines of communication open between yourself and other substitute decision-makers and, if possible, other important people in the Appointer's life.

Sometimes, there are disagreements between substitute decision-makers or conflicts with other people involved in the life of the Appointer.

For example, a substitute decision-maker and a health practitioner may disagree about a decision to withdraw life-sustaining treatment. Or two substitute decision-makers may disagree about whether the Appointer would have wanted to live at home alone. Or a family member may believe that the substitute decision-maker is preventing the Appointer from maintaining an important relationship.

These are all situations where conflict can arise.

If someone who is involved in the Appointer's life has concerns about decisions or decision-makers, they can ask the Office of the Public Advocate for guidance and help. The Office of the Public Advocate has a Dispute Resolution Service that helps people to work through these types of problems and find pathways forward in the decision-making process.

If the dispute resolution process does not resolve the disagreement about decisions or decision-makers, anyone who has an interest in the life of the Appointer can make an application for the South Australian Civil and Administrative Tribunal to make Guardianship Orders.

What if I no longer want to be a substitute decision-maker?

If you do not want to continue in the substitute decision-maker role, you must let your Appointer know in writing. This is called **renouncing**.

If there is more than one substitute decision-maker, and you do not have to make decisions together, one can decide not to continue (renounce), and the other(s) can continue. The Advance Care Directive is still valid.

If you are the only substitute decision-maker, and you do not want to continue in the role, and the Appointer is not able to make a new Advance Care Directive, you must go to the South Australian Civil and Administrative Tribunal (SACAT) to renounce.

Seeking support

If substitute decision-makers are feeling conflicted about decisions or there are disagreements with the Appointer's family or friends, seeking support can help.

Good support can help you to not feel overly burdened or alone in your decision-making. It may even help you feel more confident if you can talk to someone about how you are trying to make decisions as the Appointer would have wanted.

You may choose to talk with the Appointer's family and friends, health practitioners and other professionals. If the decision is about accommodation or personal affairs, you could also speak with the Appointer's attorney (financial and legal decision-maker, appointed under an Enduring Power of Attorney).

When seeking support, substitute decision-makers may find it helpful to talk with others about the following:

- > the Appointer's cultural identity or practices and spiritual or religious preferences
- > how the Appointer lives their life—what they enjoy doing, their values and what is important to them
- > whom the Appointer would want to stay in contact with/relationships that the Appointer would want to maintain
- > decisions the Appointer made in the past about their health or personal affairs
- > the risks, benefits and options for decisions or treatment
- > expected outcomes from a decision.

If a substitute decision-maker needs information about the Advance Care Directives legislation or their responsibilities as a substitute decision-maker, the **Office of the Public Advocate** can help.

Emotional support and self-care

Being a chosen and trusted as someone's decision-maker and helping to uphold their rights is an honour. Acting in the substitute decision-maker role can also be challenging

sometimes. Making decisions for someone else isn't always easy. You will likely need time to reflect, rest and rebuild your energy. Doing activities you enjoy and seeking support from family, friends or services can help.

You may also be a carer and be able to access a carer support group in your community.

For more information, please refer to the Carer Gateway website at www.carergateway.gov.au and search for 'looking after yourself'.

Establishing a self-care routine is important. Getting enough sleep, eating well and exercising are good foundations for self-care. Many people practise relaxation or mindfulness techniques to help them manage their thoughts and feelings.

In addition, being well organised and having all of the important information available when it is needed can help you feel more confident in making the more challenging decisions.

The next section of this guide lists many resources to help you with your valuable role.



Section 5: Resources and glossary

Useful contacts and information (websites and laws)

Adult Safeguarding Unit

Responds to concerns about South Australian adults who may be vulnerable and experiencing mistreatment.

Visit www.sahealth.sa.gov.au and search for 'adult safeguarding unit'.

Advance Care Directives Act 2013

Available on www.legislation.sa.gov.au

Advance Care Planning Australia

www.advancecareplanning.org.au

Aged Rights Advocacy Service

Free, confidential and statewide service to older people (or their representatives) who are seeking advocacy assistance to uphold their rights.

<http://sa.agedrights.asn.au>

COTA (Council on the Ageing)

Peak body representing the rights, interests and futures of older Australians.

www.cotasa.org.au

Department of Human Services Restrictive Practices Unit

For information about restrictive practices under the National Disability Insurance Scheme.

Visit www.sa.gov.au and search 'restrictive practices'.

Grief Line

Free grief support over the telephone.

griefline.org.au

Hospital Social Workers

Contact or ask at your local hospital to speak with a social worker who can provide assistance and guidance about ACD practice in hospital settings.

Legal Services Commission

Legal information, fact sheets and guidance.

lsc.sa.gov.au

National Dementia Helpline

Information and guidance about dementia.

www.dementia.org.au

Office for Ageing Well, SA Health

Office for Ageing Well takes the lead on state government ageing policy. The Office includes the voices of older South Australians as it works to safeguard their rights; create age-friendly communities and meaningful connections; challenge ageism; and respect diversity.

Visit www.sahealth.sa.gov.au and search for 'office for ageing well'.

Office of the Public Advocate

Information service and dispute resolution for matters related to Advance Care Directives.

OPA is an independent office of the South Australian Government. OPA promotes the rights and interests of people who may need assistance with decision-making. Other services include providing information, advocacy, investigation and dispute resolution. OPA can also be appointed as a guardian of last resort in situations where people may not have decision-making capacity.

Contact the OPA Information Service on 1800 066 969.

OPA has many fact sheets you can download from their website, www.opa.sa.gov.au

Plan Ahead

Explains the importance of documenting your wishes using the legal tools (Advance Care Directive, Enduring Power of Attorney, will, and organ and tissue donation) to ensure they are respected if you cannot speak for yourself.

Visit www.sahealth.sa.gov.au and search for 'plan ahead'.

South Australian Civil and Administrative Tribunal (SACAT)

Resolves issues within specific areas of law.

www.sacat.sa.gov.au

The Carer Gateway

Emotional, practical and financial support for carers.

www.carergateway.gov.au

Translating services

For help supporting people who speak languages other than English.

www.translate.sa.gov.au

www.tisnational.gov.au

Glossary of terms

Accommodation

Accommodation means a place where someone lives or stays.

Administration Order

The South Australian Civil and Administrative Tribunal can make an Administration Order when someone does not have the legal capacity to make their own financial, legal and/or property decisions.

The Administration Order appoints one or more administrators to make decisions for the person, either together or separately.

Advance Care Directives

An Advance Care Directive (sometimes referred to as an ACD) is a legal document that outlines the wishes and instructions or decisions about a person's health care, preferred living arrangements and personal affairs. It can also include end-of-life decisions and treatment the Appointer does not want.

Advance Care Directives do not cover decisions about finances, property or legal affairs.

If the Appointer is unable to make a decision for themselves, their substitute decision-maker should use the information in the Advance Care

Directive to make the decision the Appointer would have made, if they were able.

Advance Care Planning documents (Enduring Power of Guardianship, Medical Power of Attorney and Anticipatory Direction documents) made prior to 1 July 2014 are still valid and are treated as Advance Care Directives.

Appointer

In this guide, the 'Appointer' refers to the person who has completed their Advance Care Directive and appointed their substitute decision-maker(s).

Attorney

A financial decision-maker, appointed under a Power of Attorney document (see General Power of Attorney and Enduring Power of Attorney).

Authorised witness

The *Advance Care Directives Act 2013* says that an Advance Care Directive must be witnessed and signed by an authorised witness. The Act says that:

- > the witness cannot have an interest in the Appointer's estate.
- > the witness cannot be the Appointer's doctor or someone else in charge of their care.

The [Advance Care Directives Regulations 2014](#) (available at www.legislation.sa.gov.au) includes a list of professionals who are allowed to act as an authorised witness.

Binding refusals

If the Appointer has outlined medical treatment that they do not want to receive or health outcomes that they want to avoid, the substitute decision-maker must follow these instructions. These are called binding refusals.

Decision-making capacity

Decision-making capacity is how well someone can manage the different parts of the decision-making process. If someone is not able to make a decision for themselves (the *Advance Care Directives Act 2013* uses the term 'impaired decision-making capacity'), they may struggle to:

- > understand some or all of the information relevant to a decision
- > understand the consequences of a decision
- > remember the relevant information, even for a short time
- > use this information to make a decision
- > communicate their decision to others in some way.

Someone may be able to make one decision and not another. Decision-making capacity refers to the ability to make a particular decision. This is called 'decision-specific capacity'.

Someone may still have the capacity to make a particular decision, even if the following applies:

- > They are not able to understand certain types of information.
- > They can only remember information for a short period of time.
- > They make a decision that results in a negative outcome.
- > Their ability to make decisions changes over time.

Depending on a person's capacity to be involved in a particular decision, substitute decision-makers should choose the following:

- > a supported decision-making approach, which involves the Appointer in the decision-making process as much as possible; or
- > substitute decision-making, where the Appointer is not able to be actively involved in the decision-making process, and the substitute decision-maker makes the decision that the Appointer would have made if they were able.

Dispute Resolution Service

The Dispute Resolution Service (DRS) is a service provided by the Office of the Public Advocate. The DRS helps people to work through disagreements about health, accommodation, and lifestyle decisions.

The dispute resolution process is voluntary, confidential, and future-focused. It involves giving information about legislation and assisting people to explore and resolve decision-making issues through mediation.

Enduring Power of Attorney

An Enduring Power of Attorney is a legal document. It says that someone (called an attorney) can make financial and/or legal decisions for another person (the Appointer) if the Appointer does not have the legal capacity to make those decisions for themselves.

An Enduring Power of Attorney does not cover decisions about a person's health, accommodation or personal affairs. Enduring Powers of Attorney can be registered with the Lands Titles Office.

An Enduring Power of Attorney is still valid if the Appointer loses decision-making capacity.

Enduring Power of Guardianship

Enduring Powers of Guardianship, Medical Powers of Attorney and Anticipatory Directions were the documents used in the past to write down advance care wishes. They are no longer used, but if they were completed and signed prior to 1 July 2014, they are still legally valid. However, they are now called Advance Care Directives (ACDs) and will be treated as if they were made under the current Advance Care Directive legislation.

Family of choice

This term refers to a non-biologically related group of people who are established to provide ongoing social support. Unlike a 'family of origin' (the biological family or that in which one is raised), a family of choice is based on chosen bonds, not biological ones.

General practitioner (GP)

A General Practitioner (known as a GP) is a doctor who is qualified in general medical practice. They are often the first point of contact for someone who feels sick or has a health concern.

Geriatrician

A geriatrician is a doctor with specialist training in the health of older people (geriatric medicine). They diagnose and treat age-related medical conditions.

Guardianship Orders

If a decision needs to be made for a person who is not able to make the decision themselves, the South Australian Civil and Administrative Tribunal (SACAT) can make a Guardianship Order.

A Guardianship Order:

- > Is a legal document.
- > Can appoint one or more guardians to work together or separately.
- > Can appoint a guardian to make specific decisions, for example about accommodation, health care and/or lifestyle decisions.

More information and fact sheets about guardianship and Guardianship Orders are on www.opa.sa.gov.au

Health care

In the *Advance Care Directives Act 2013*, health care means any care, service, procedure or treatment (including medical treatment) provided by, or under the supervision of, a health practitioner for the purpose of diagnosing, maintaining or treating a person's physical or mental condition.

Health practitioner

The term 'health practitioner', in the *Advance Care Directives Act 2013*, means a person who practises a health profession (according to the Health Practitioner Regulation National Law (South Australia)) and/or any other profession or practice declared by the regulations of the Act to be included in the scope of this definition.

Impaired decision-making capacity

The Act says that someone has 'impaired decision-making capacity' if they are not able to manage parts of the decision-making process, in relation to a particular decision. Someone may have impaired decision-making capacity if they have difficulty with parts of the following:

- > understanding some or all of the information that is relevant to a decision
- > understanding the consequences of a decision
- > remembering the relevant information, even for a short time
- > using this information to make a decision
- > communicating their decision to others in some way.

For more information, see 'decision-making capacity'.

Informed consent

Informed consent is when a person voluntarily decides to agree to a health care treatment, procedure or other intervention that is made in the situations below:

- > following the provision of accurate and relevant information about the health care intervention and alternative options available; and
- > with adequate knowledge and understanding of the benefits and material risks of the proposed intervention relevant to the person who would be having the treatment, procedure or other intervention.

Ensuring informed consent is properly obtained is a legal, ethical and professional requirement on the part of all treating health practitioners and supports person-centred care. Good clinical practice involves ensuring that informed consent is validly obtained and appropriately timed.

Informed consent is integral to the right to information in the Australian Charter of Healthcare Rights and is recognised in Professional Codes of Conduct. Additionally, the National Safety and Quality Health Service Standards require all hospitals and day procedures services to have informed consent processes that comply with legislation, lawful requirements and best practice.

Medical Power of Attorney

Enduring Powers of Guardianship, Medical Powers of Attorney and Anticipatory Directions were the documents used in the past to write down advance care wishes. They are no longer used, but if they were completed and signed prior to 1 July 2014, they are still valid. However, they are now called Advance Care Directives (ACDs) and will be treated as if they were made under the current Advance Care Directive legislation.

A substitute decision-maker appointed under a Medical Power of Attorney is only able to make health care decisions, even though the document is treated as an Advance Care Directive.

Memory Support Unit

A Memory Support Unit is also known as a secure unit or a dementia care unit. It is a specialised type of accommodation in a residential aged care facility. The environment in a memory support unit is set up to support a person who is experiencing memory loss.

Person Responsible

A 'Person Responsible' is the term for those people who are able to make health care decisions on behalf of someone who is not able to give consent for their own treatment and does not have an Advance Care

Directive or has not appointed a substitute decision-maker.

A Person Responsible has legal authority and can provide/refuse consent according to the following legal order:

- > A guardian with health care decision-making powers appointed by the South Australian Civil and Administrative Tribunal
- > A prescribed relative with a close and continuing relationship, who is available and willing to make the decision(s)
- > A close adult friend, who is available and willing to make the decision(s)
- > An adult who is charged with overseeing the ongoing day-to-day supervision, care and well-being of the person and who is available and willing to make the decision(s) (not including chemical restraint).

A frequently asked questions fact sheet about the role of a 'Person Responsible' is available from the www.sahealth.sa.gov.au – search for 'consent act changes'.

Personal affairs

A substitute decision-maker will sometimes need to make a decision about their Appointer's personal affairs. Personal affairs are different to health care, financial and

accommodation decisions. They are more day-to-day matters, such as:

- > who the Appointer would like to maintain contact and spend time with,
- > what relationships and activities are important to them,
- > their values around personal grooming and comfort, and
- > cultural and religious beliefs and practices.

Power of Attorney

A General Power of Attorney is a legal document. It says that someone (called an attorney) can make financial and/or legal decisions for another person (the Appointer) for a specific period of time. An example of this is the attorney being able to access the Appointer's bank account to complete a transaction while the Appointer is overseas.

A General Power of Attorney does not cover decisions about the Appointer's health, accommodation or personal affairs.

A General Power of Attorney is no longer valid if the Appointer loses decision-making capacity.



Principles of the *Advance Care Directives Act 2013*

The Principles are a set of guidelines listed in Section 10 of the *Advance Care Directives Act 2013*. These principles must be taken into account when using the Act to make a decision, make a judgement, or resolve a dispute.

Renouncing

If a substitute decision-maker renounces their role, this means that they tell the Appointer, the South Australian Civil and Administrative Tribunal and any other appointed substitute decision-makers that they do not want to make decisions for the Appointer anymore.

Restrictive practices

When someone restricts the rights and freedoms of a person they are caring for or stops them from doing something they want to do (to protect their safety or the safety of others), this is called a restrictive practice.

South Australian Civil and Administrative Tribunal (SACAT)

SACAT is a Tribunal that resolves issues within specific areas of the law. These areas include Advance Care Directives, Guardianship Orders and Administration Orders.

Special powers

Special Powers Orders are legal orders made by the South Australian Civil and Administrative Tribunal. They allow a guardian or substitute decision-maker to (a) say where someone will live; (b) say that someone is not allowed to leave a particular place; and/or (c) say that force can be used, so that medical or dental treatment can be given.

These powers are very restrictive and used as a last resort. They must only be made if there is a risk to someone's health or safety.

Supported Decision-Making

Even if the Appointer has limited decision-making capacity, the substitute decision-maker should still talk with them and involve them in decisions as much as possible. This promotes the Appointer's right to participate in decisions that affect their life. When substitute decision-makers make decisions alongside Appointers in this way, this is called a supported decision-making approach.

Voluntary Assisted Dying

Voluntary Assisted Dying means that you can choose to take a medication, or have one given to you, that will cause your death.

Voluntary Assisted Dying is an end-of-life choice available to eligible South Australians under the *Voluntary Assisted Dying Act 2021*.

Will

A will is a legal document that says how someone would like their belongings or estate to be managed after they have died. It can give instructions, for example, about who will care for children or pets. It can also appoint an executor to make sure the instructions are carried out.

This guide is available online at
www.opa.sa.gov.au/sdm-toolkit-guide



www.ausgoal.gov.au/creative-commons

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