



ADVANCE CARE PLANNING
FOR INDIVIDUALS AND
FAMILIES

HANDBOOK

MODULE 4



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MODULE FOUR SUBSTITUTE DECISION MAKERS



INTRODUCTION

After you have made your decisions about the type of care you do or do not wish to receive, the next most important thing to record in your Advance Care Plan is who you have chosen as your Substitute Decision Maker.

Unlike Enduring Powers of Attorney or Guardianship, your Advance Care Plan does not automatically empower another person to make medical treatment decisions for you, unless you specifically name them as your preferred Substitute Decision Maker or Makers.

In this Module you will learn about choosing a Substitute Decision Maker and what it means for someone to be named as a Substitute Decision Maker.

More detailed information can be found by speaking with your lawyer or go to <https://end-of-life.qut.edu.au>

HOW DO I CHOOSE A SUBSTITUTE DECISION MAKER?

As discussed briefly in Module One, there is a lot to consider when choosing your Substitute Decision Maker. There are legal requirements and there are emotional aspects.

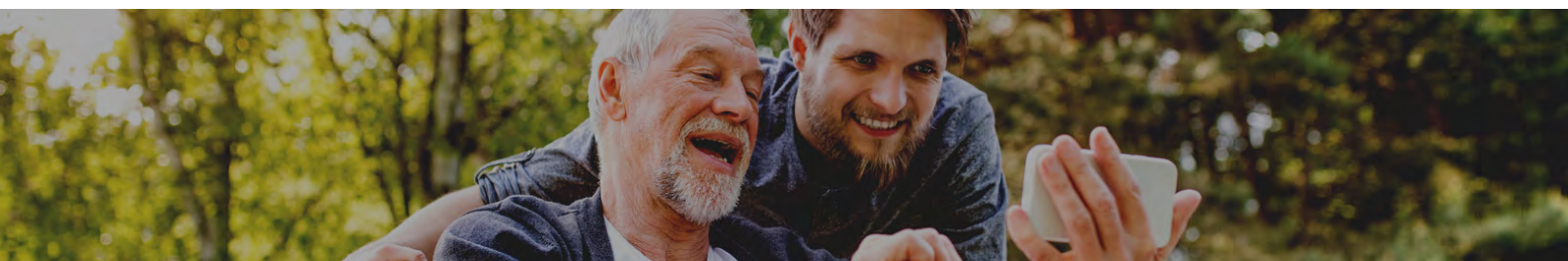
Speak with your lawyer, your doctor or go to <https://end-of-life.qut.edu.au> to learn more.

In Australia, a substitute decision-maker can be chosen in one of three ways:

- * by you
- * assigned to you by the law in the absence of an appointed substitute decision-maker
- * appointed for you (e.g. a guardian appointed by a guardianship tribunal)

In general, your substitute decision maker should be:

available (live in the same city or region) or readily contactable over the age of 18
prepared to advocate and make decisions clearly and confidently on your behalf when talking to doctors, other health professionals and family members comfortable with encouraging you to talk through your preferences with them, your family members and close friends



WHO SHOULD I CHOOSE AS MY SUBSTITUTE DECISION MAKER (SDM)?

In an Advance Care Plan or Advance Care directive made at common law- in all states of Australia, you can appoint a range of people as your substitute decision maker, for example:

- spouse or de facto spouse
- unpaid carer
- nearest relative or friend with whom you have a close personal relationship

If you already have appointed an Enduring Guardian or an Enduring Power of Attorney for health, it is a good idea to also appoint them as your SDM for your Advance Care Plan. This keeps things simple!

You need to choose someone you trust and feel will be capable of both communicating and carrying out **your** wishes.

Your Substitute Decision Maker should be a person you can talk to about difficult and confronting subjects - such as the use of feeding tubes, and life support - without judgment or avoidance. Ask yourself: “ Does this person know me well enough to know what decisions I would make about my medical care, and act in a way that is in my best interest?”

Questions to ask yourself about a potential substitute decision maker might be:

What if I do not want to be put on life support? Would they be able to advocate to my doctors for my choice? Even if it was not what they personally wanted? Even in an emotional and stressful situation?

What if I want all care possible to be given to me regardless of the outcome? Are they aware of that? Are they aware that sometimes the medical care wished for in an Advance Care Plan is not medically appropriate. How would they cope with that?

It is vital that you talk to your intended SDM about scenarios like this and ensure they understand **your** values, beliefs, acceptable outcomes and health care preferences in full.

They should be willing and able to communicate **your** preferences and the reasons behind them in a respectful way to a range of decision makers and to participate in any health care decision making on your behalf.

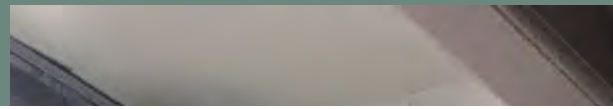
CAN I APPOINT MORE THAN ONE SUBSTITUTE DECISION MAKER?



Yes, under both **Common Law**, and most states and territories' statutory laws, just as you can appoint more than one Enduring Guardian. Check with your lawyer or <https://end-of-life.qut.edu.au/>

The second or even third substitute decision maker can be appointed as a joint substitute decision maker, or as an alternative substitute decision maker.

Joint substitute decision makers are required to make decisions together and equally, that is jointly. Whereas the alternative substitute decision maker will be called on to make a decision if your main decision maker is unable to make decisions on your behalf.



WHY WOULD I APPOINT MORE THAN ONE SUBSTITUTE DECISION MAKER?

Many people appoint two or even three substitute decision makers. This is because your substitute decision maker may have to make decisions about your life and death, and may have to make them quickly. This is far more stressful than the everyday health care decisions they make as your Enduring Guardian, or your Enduring Power of Attorney for Health.

For example your spouse may be comfortable making everyday health care decisions as your Enduring Power of Attorney for Health Matters, but they may find it overwhelming to make a decision to enact your Advance Care Plan which may be more about life and death. If there is a joint SDM appointed, for example your son or daughter, they have a second person who knows your wishes and who can assist them to make those more difficult decisions.



WHEN DO I CHOOSE A SUBSTITUTE DECISION MAKER?

You should include the name(s) of your chosen Substitute Decision Maker(s) in your Advance Care Plan. You should consider who you would like, and speak to them about it, before committing their name to paper.

It is important that they fully understand the role before accepting.

You should consider who else you might want to appoint in case your first choice does not feel able to take on the responsibility.



WHAT IS THE ROLE OF A SUBSTITUTE DECISION MAKER?

Being a substitute decision maker is a big responsibility. They are responsible for understanding your wishes and advocating for them to be carried out, so that decisions made about you, are aligned with your Advance Care Plan.

When decisions are difficult or your Advance Care Plan does not provide specific instructions for a given scenario, they have to consider your plan as best they can, in consultation with your care providers and doctors. This includes making decisions on your behalf about whether life-sustaining treatments should be provided or withdrawn.

With that in mind, your SDM should talk with you fully about your goals, wishes and care preferences to ensure they are clear about what you want and to offer you a sounding board or different perspectives. They can check to make sure you are making your decisions from a sound frame of mind, and later they can attest to the fact that you appeared to understand the consequences of your decisions, had a sound frame of mind when you were making and explaining decisions, and good reasons for your decisions.

Just as you should regularly review your plan, so too you should regularly discuss any changes in your situation and choices with your SDM, so they are kept up to date in case something happens before you are able to update your plan.

KEEPING THEM IN THE LOOP

Your ACP should be reviewed regularly - either every 12 months as a minimum or whenever there has been a major change in your life, health, family, or medical circumstances.

When you want to update your documents- update your conversations too!

Have a chat with your SDM(s) about why you changed your mind.

Make sure they have a copy of the new plans and understand why you made the changes.

