ADVANCE CARE PLANNING FOR INDIVIDUALS AND FAMILIES

HANDBOOK

MODULE 1

TOUCH STONE LIFECARE

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MODULE ONE

THE BASICS

INTRODUCTION

When it comes to Advance Care Planning, so many of us say ‘There’s always time to do it later’ until suddenly it is too late, and our families have to make decisions about us without knowing what to do.

Nobody wants that and nobody wants to put their families through that or to risk losing control over what happens to us when we are at our most vulnerable.

And yet it often takes a life-limiting or life-threatening condition for us to be willing to think about, and discuss how we want to spend those most important last few days, weeks or months.

Ideally, the process of developing your Advance Care Plan should begin as soon as you are 18, and should be revisited and revised regularly throughout your life.

But no matter where you are in your life’s journey, now is a good time to start thinking about what is most important in your life and to learn how to document and share those goals and priorities in a way that makes sense to others.

This Module will introduce you to Advance Care Planning, its benefits and core components. At the end of this section, there will be a short series of questions about what we have covered.

WHAT IS AN ADVANCE CARE PLAN?

An Advance Care Plan (ACP) is a combination of your goals, values and beliefs (including cultural or religious ones) that will guide the medical intervention you receive in an emergency or towards the end of your life. It is your way of communicating to your loved ones and doctors what medical treatment you do and do not wish to receive in the event that your health deteriorates so much that you might die.

It helps to ensure any treatment they do give you, honours your personal beliefs and values and life goals, and decisions are made about you by people who know what is most important to you.

It is only ever used if you become physically or mentally unable to communicate for yourself, and people need to make decisions about what care to give you.

An Advance Care Plan consists of two key elements:

1. **The Advance Care Directive – the document in which you outline your wishes**
2. **The name(s) of your Substitute Decision Maker(s)**

But to make your Advance Care Plan really work for you, you need to also take the time to discuss in depth the details of the plan with your family, doctors and any one else who may be involved in your future care. It is also vital that you ensure anyone named as a Substitute Decision Maker understands what is involved and agrees to be one for you.

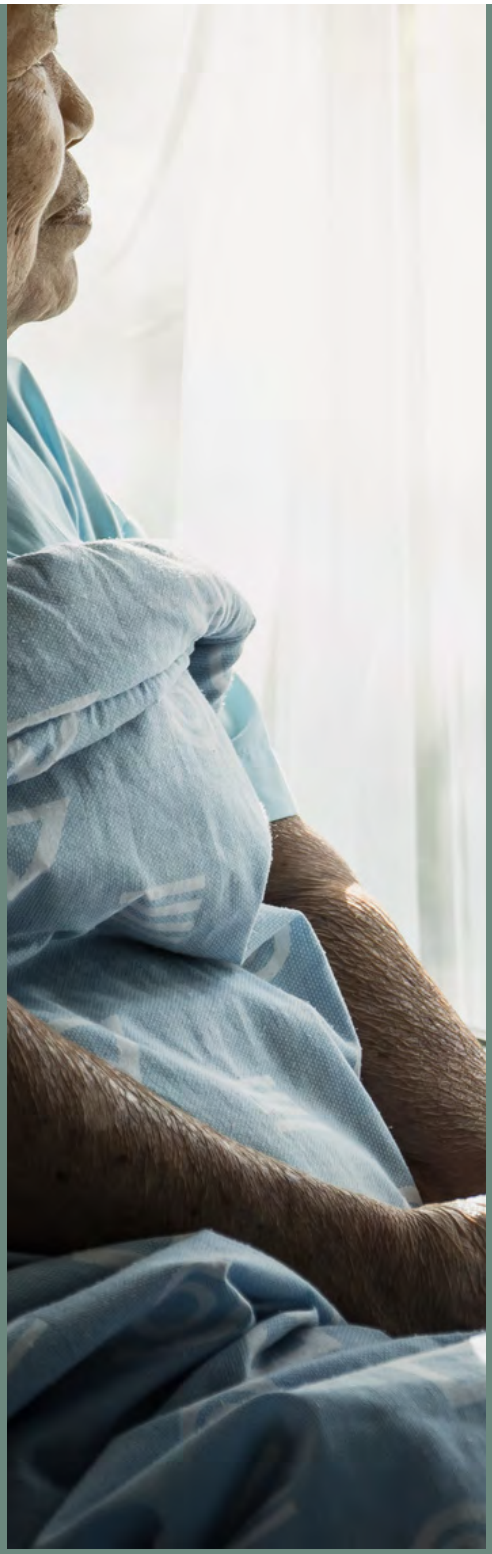
So, in summary, Your Advance Care Plan is a combination of your goals, values and beliefs that will guide the medical intervention you receive in an emergency or towards the end of your life.

An Advance Care Plan is sometimes also known as a Living Will, an Advance Care Directive, Advance Health Plan or Statement of Choice depending on your Country or State.

WHEN IS AN ADVANCE CARE PLAN USED?

An ACP only comes into effect when you are unable to make – or voice – your own decisions. You may lose this decision making ability over a period of time because of illness, the process of dying, or dementia, or you may lose it in an instant because of an accident or sudden health condition.

For loved ones, having to make life and death decisions about you can be extremely stressful if they do not know what you would want – particularly if there are conflicting opinions about what you would want. It is also hard for them to make decisions when they are themselves grieving or panicked, or have to discuss with doctors about health conditions and terminology that they are unfamiliar with.



WHAT DIFFERENCE DOES IT MAKE?

When an Advance Care Plan is available, doctors can provide care more quickly...they do not have to spend time telephoning around seeking information, waiting for relatives to be found and contacted, having lengthy conferences, or negotiating conflict between family members. Instead they can start treatment more quickly and more efficiently.

That means they can get on top of pain more quickly, provide fluid therapy to avoid dehydration and the delirium that can occur, provide earlier surgery or antibiotic therapy if that is indicated in the Advance Care Plan, and avoid painful interventions such as catheterisation or intubation if that is not what you want. In short, if doctors have access to your up to date personalised plan, they can put themselves in your shoes and make faster and better decisions about you; they can start good quality treatment earlier; and minimise your suffering faster. In fact, statistics show that you will have a better health outcome if you have an ACP available as well.

It is incredibly stressful for loved ones when they have to make life and death decisions under these conditions – particularly if there are conflicting opinions about what you would want. This in turn wastes valuable time which could be better used to treat you in the way you would want.

CAN THEY BE NEGATED OR CHALLENGED BY ANYONE?

If your family, doctors and trusted advisors are aware of – and have access to – your most recent Advance Care Plan then no, they cannot ignore your written wishes. By law in every state in Australia, the doctors must consider your advance care plan when making any decisions about you. And they must make those decisions from your point of view, as if they were in your shoes.

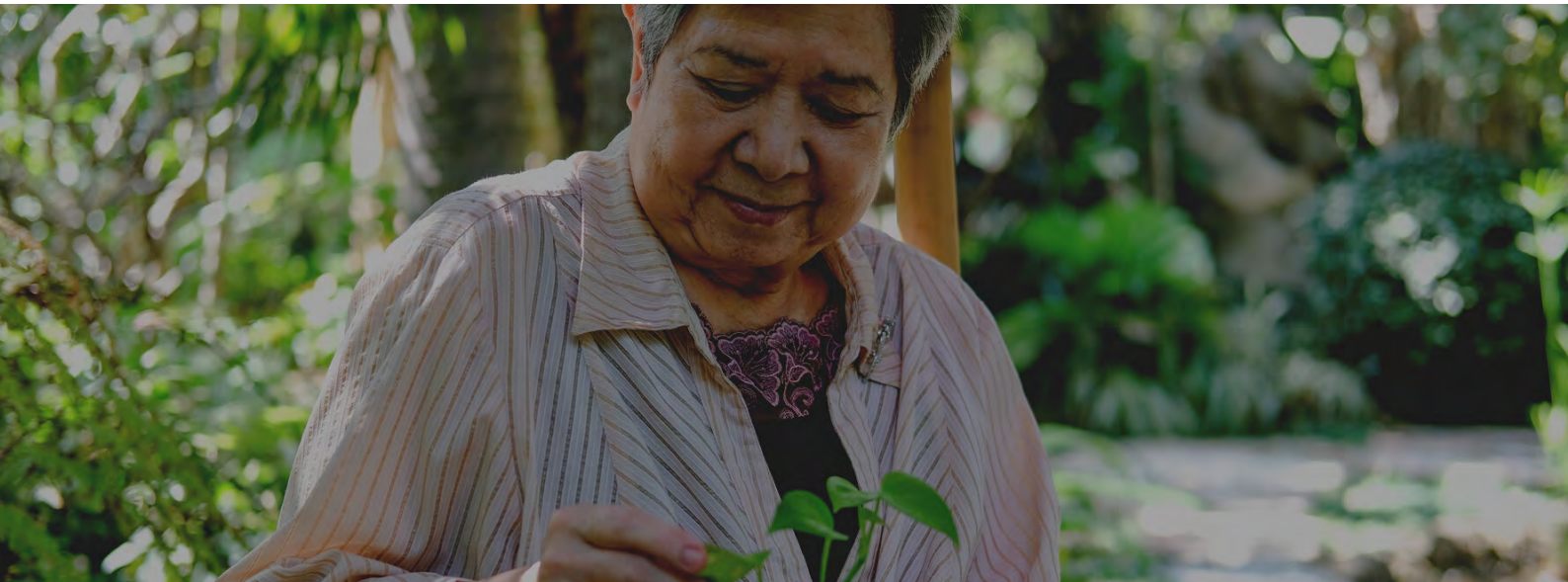
A family member is only entitled to make a medical treatment decision on your behalf if they are also your substitute decision-maker/medical treatment decision maker/person responsible at law.

Like your healthcare provider or doctor, your substitute decision maker must, under law, consider your Advance Care Plan if you lose decision-making capacity. Even if they are a family member, they cannot ignore your Advance Care Plan.

However, if anyone is concerned about your decision-making capacity at the time of making your Advance Care Plan (including your family), they might challenge it.

For example a health practitioner might challenge your Advance Care Plan if they doubt its validity, or if it does not apply to the particular circumstances at hand. They might claim that it is out of date, does not make sense, or contradicts things you have said to family members in recent times.

Because of this, it is important to ensure anyone who may play a role in your future medical care is included in the discussion around your Advance Care Plan and kept up to date with your wishes. Each state and territory has different legal mechanisms to do this, whether by application to a court or tribunal.

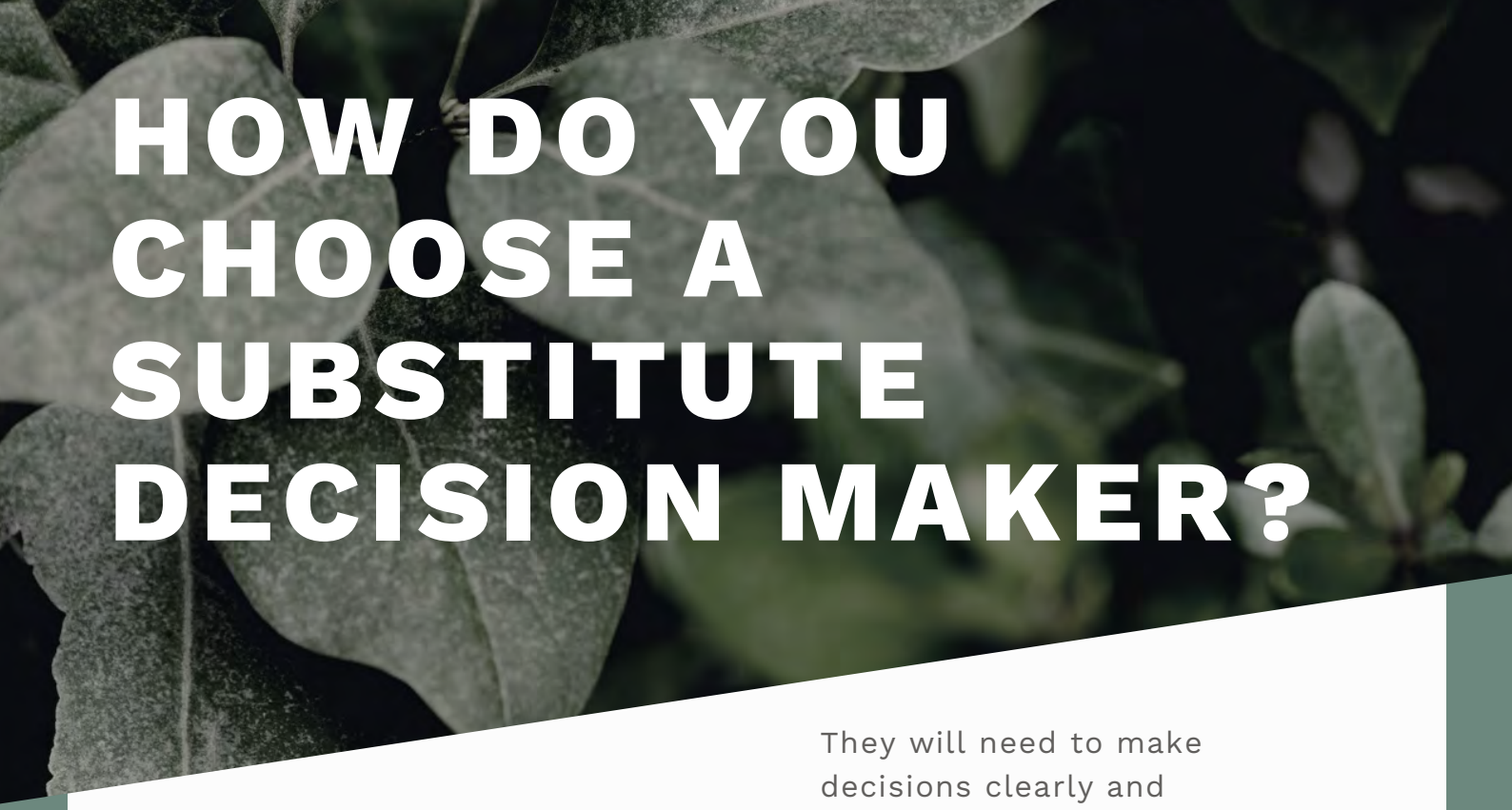


WHO SHOULD CREATE ONE?

EVERYONE OVER THE AGE OF 18.

However they are especially important for people who are older, frail, have a chronic illness, multiple diseases, early cognitive impairment, or are approaching their end of life.

Given the unpredictability of life, it is best to start your plan whilst you are healthy and have the mental capacity and time to discuss your wishes with family, doctors and trusted advisors.



HOW DO YOU CHOOSE A SUBSTITUTE DECISION MAKER?

There is a lot to consider when choosing your Substitute Decision Maker. This will be covered in more detail in Module Three.

In Australia, there are various requirements in each state and territory so it is important that you review your local requirements but in general, your substitute decision maker should be:

- available (live in the same city or region) or readily contactable
- over the age of 18
- willing and able to advocate for you and to discuss with senior doctors what you would want.

They will need to make decisions clearly and confidently (and sometimes quickly) on your behalf. So when you choose a substitute decision maker you need to give them access to your plan so they understand it, and discuss why you have made the choices you have.

If they can say to the doctors - 'I have had these conversations about this plan with this person, and I know what they want', then they suffer less stress, your doctors can have confidence in them, and you will suffer less because you will receive faster, better and more personalised care.

You may also choose a second person (an alternate substitute decision-maker). They will be called on if your main decision maker is unable to make decisions on your behalf or have jointly appointed them.

HOW OFTEN DOES IT NEED TO BE UPDATED?

You should update your Advance Care Plan regularly - at least every 12 months and after any major change in circumstances (health or life or otherwise). Our feelings about many subjects change over the course of our lives. You might suddenly become a grandparent and want to stay alive for longer, despite ill health. You might suffer multiple small strokes, and not want to live with the consequences of a further major stroke. You might not have been able to bear the thought of losing your independence when you were young, but as you become older, it is not so concerning to you and less of a worry. It is natural that as you age, your opinions surrounding quality of life versus life length change. This is why you must update your plan and your choices regularly- at least every 12 months. And as soon as you update your plan, make sure that you destroy any old copies and share the updated copy with anyone who would have a copy of your previous advance care plan.

WHO SHOULD YOU SHARE YOUR ADVANCE CARE PLAN WITH?

You should discuss and share your Advance Care Plan with your closest family members, doctors and any trusted advisors such as a Financial Planner, Lawyer and whoever you have appointed as your Power of Attorney, Enduring Guardian or Substitute Decision Maker. Many people have close relationships with a neighbour or good friend, and these people can be included in your advance care planning contacts too.

It is vital that anyone who may be responsible for managing your care at the end of your life is kept up to date with your wishes. This helps to avoid extra stress and confusion amongst family and means doctors can provide you the best care quickly without any delay.

WHAT ABOUT ENDURING GUARDIANS, HEALTH PROXIES AND LAWYERS?

You may have already appointed an Enduring Guardian with your lawyer. This person is also known in some states as an Enduring Attorney for Health Care Matters, Attorney for Personal/Health Matters, Substitute Decision Maker, Medical Treatment Decision Maker. This is the person you appoint to make decisions about the medical care you receive when you cannot make those choices for yourself, and they will also make decisions about medical care at the end of your life.

Importantly, they must use your Advance Care Plan when making decisions, if it is available. You may therefore want your Enduring Guardian or Health Attorney to also be named as your Substitute Decision Maker in your Advance Care Plan, and make sure they know and understand the choices you have made.

Some people do not have an Enduring Guardian or may have only one, but may name more than one Substitute Decision Maker in their Advance Care Plan. This is because the decisions about end of life care can be difficult to make. For example, your Enduring Guardian may be your spouse but you do not want them to make decisions about your end of life all alone- so you appoint an extra Substitute Decision maker to help them.

WHO SHOULD START THE CONVERSATION ABOUT AN ADVANCE CARE PLAN?

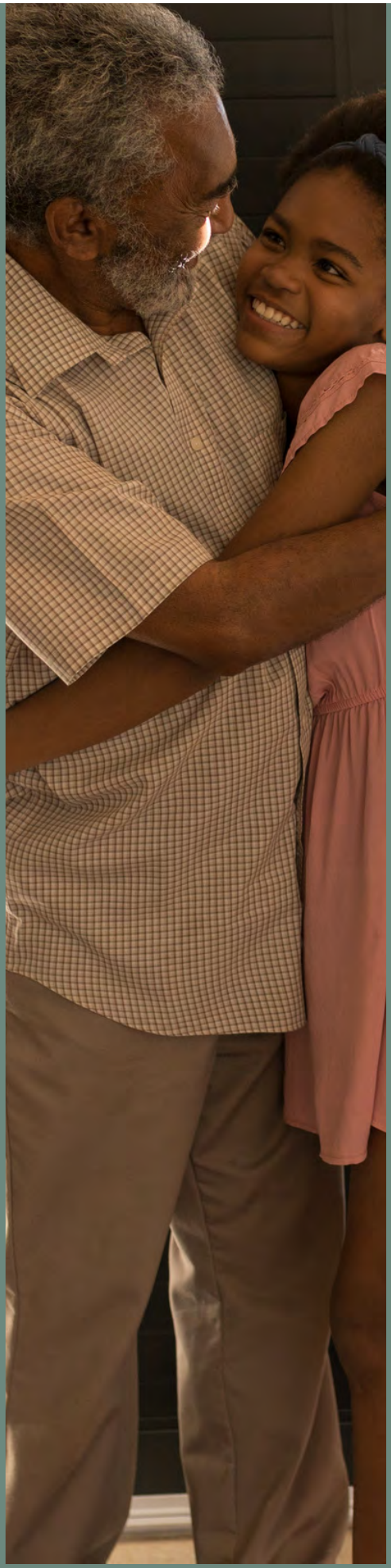
The reality is, everyone has a role to play when it comes to discussing and creating Advance Care Plans - yours or a loved one's. It is about recognising the opportunities and understanding the potential barriers ahead of time and preparing for the conversation to give yourself the best chance of a successful and constructive conversation.

There is no "perfect" way to start a conversation about death and dying. Everybody is different. Some people want to discuss their plans with their whole family all at once. Others prefer to have one on one conversations. Some would like to do it casually over a meal, others over a Zoom call, or a formal family gathering.

Some people may object to a member of their family introducing the topic, thinking it is none of their business whereas still others might delight in sharing their personal values and life meaning with grandchildren, or other important people. Still others would prefer their lawyer to disclose to members of their family, on their behalf, what their wishes are.

Whatever you choose, it is vitally important that you inform anyone who will be asked to make decisions about you that you have an Advance Care Plan, and educate them on the choices you have included in it.

Here are some ideas about how you can plan the conversation to help make it easier for everyone:



- Think about who you would like to have in the room – would you rather have immediate family or perhaps some trusted friends as well? One on one conversations or all sitting down together?
- Will the conversation be over a meal such as dinner? Or a casual get together. At home or in a public place?
- Would you like to run the conversation as a meeting, going around the group and giving everyone equal time to respond and react, or would you rather keep it informal? Maybe make time for a follow get together.
- How will you start the conversation? Will you tell a story such as what it was like for you when you were looking after your elderly parent?
- If you are the person trying to encourage another to make an advance care plan-how about starting with why it is important to you for them to have a plan. For example " Mum, I am concerned that something might happen to you and I would have to talk to the doctors about what medical treatment you would want. But I really don't know the answer to that question. Can we please have a chat about what you would want me to do for you if you got really sick really quickly and couldn't talk for yourself?
- Start by simply asking those you have chosen to be part of the conversation.
- You may organise a time that allows you all to come together without any time pressures so that you can calmly talk about your end-of-life plans, or you might grab an opportunity, a serendipitous moment when the conversation comes up naturally and unplanned.
- Don't expect that you will be able to answer all questions in one go. It may take several discussions over time.

In Module Five, we will take you through different types of approaches including how to identify and avoid possible conflict as well as effective listening skills which you may find useful for any discussions you are having about an Advance Care Plan.