



ADVANCE CARE PLANNING
FOR INDIVIDUALS AND
FAMILIES

HANDBOOK

MODULE 5



TOUCH
STONE
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**MODULE
FIVE
STARTING THE
CONVERSATION**



INTRODUCTION

When it comes to end of life planning, starting the conversation with your loved ones may seem like the hardest part. But it doesn't have to be.

In this Module, we'll take you through when and who should start the conversation. We'll discuss ways to open the lines of communication, and the kinds of things to be aware of when discussing aspects of your own, or a loved one's future plan.

ROLES AND OPPORTUNITIES

The first question many people ask is - Do I need to have this conversation?

Whether or not it is your own plan, or someone else's the simple answer is: yes.

The "why", depends on the situation you are in.

When it comes to talking about end-of-life planning, we all have a role to play in making it an open, natural and easy conversation to have.

For example:

As a GP: Discussing an end-of-life plan should be a natural part of the long term relationship you have with your patient. You see them through every stage of their care and know about their family history and personal situation. You can chat to them about their long term wishes and goals in a way that doesn't mean you want to break some bad news or you are expecting them to die imminently...but if there are things on the horizon that impact their health and wellbeing, you are best placed to start them on the journey of planning.

As a trusted advisor: Your clients come to you for your expertise and with the knowledge you will look out for their best interests. If they are making a change to their will, want to change their long term investments or are seeking new treatment for an injury or ailment, these are all moments that give you the chance to have a conversation around end-of-life planning.

As a parent: Discussing death and dying starts when your child's first pet passes away or a grandparent dies. Being able to prepare our children for the inevitable is perhaps best done in a more gradual sense but especially as they reach the age of 18. You should be talking about the "big stuff" that they themselves need to consider.

As a child: The last thing any of us want to do is to imagine our elderly parents suffering. And facing the reality of life without them can be difficult. However, we know life can change quickly and therefore the ability to have an open conversation is important. As our parents age and their health becomes frailer, the chances of being unprepared in an emergency increase. Talking provides everyone with peace of mind...

As a partner: You have committed your life to your loved one. You have agreed that this is the person you want to face all life's challenges with. You know their favourite colour, favourite meal, beloved childhood pet and discussed their highs and lows....so being able to plan the future together means being prepared for everything - including death.

And as a good friend: You are the emotional support and sounding board for those around you. When they open up about an issue or problem in their life, don't be afraid to show you care enough to talk to them about something deeper.



GETTING THE BALL ROLLING

Unfortunately, there is no “perfect” way to start a conversation about death and dying. Everybody is different and, in a family, some might handle it better than others. But it is important that you inform them of what you are doing and educate them on the decisions you are making. Why not spend some time and plan the conversation as much as you can to help make it easier?

- Think about who you would like to have in the room. Would you rather have immediate family or perhaps some trusted friends?
- Start by simply asking those you have chosen to be part of the conversation.
- 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.
- Don't expect that you will be able to answer all of their questions after one sit down. It may take several discussions over time.



BARRIERS TO TALKING

There are many barriers to having a conversation about advance care planning or end-of-life planning. If we go back to the various roles of people in the discussion process, in each scenario there will be barriers to overcome and it is important to have thought about these before you begin, in order to have the best opportunity to create a positive environment for discussion.

It might be that people do not feel it is their or even your place to start asking about this subject. Or it might be that they feel uncomfortable in themselves. Maybe you do not feel correctly trained, or that as a child you feel your parents might think you are already planning life without them.

Whether you are talking to someone or being spoken to, you need to set the scene and be ready to answer the big questions without fear.

It takes more than one conversation. Talking about advance care planning needs discussing many times over - not just once.

AVOIDING CONFLICT

As we've said throughout this Module, creating an opportunity and setting the scene will give yourself the best chance to have a positive conversation. It is also about understanding "your audience."

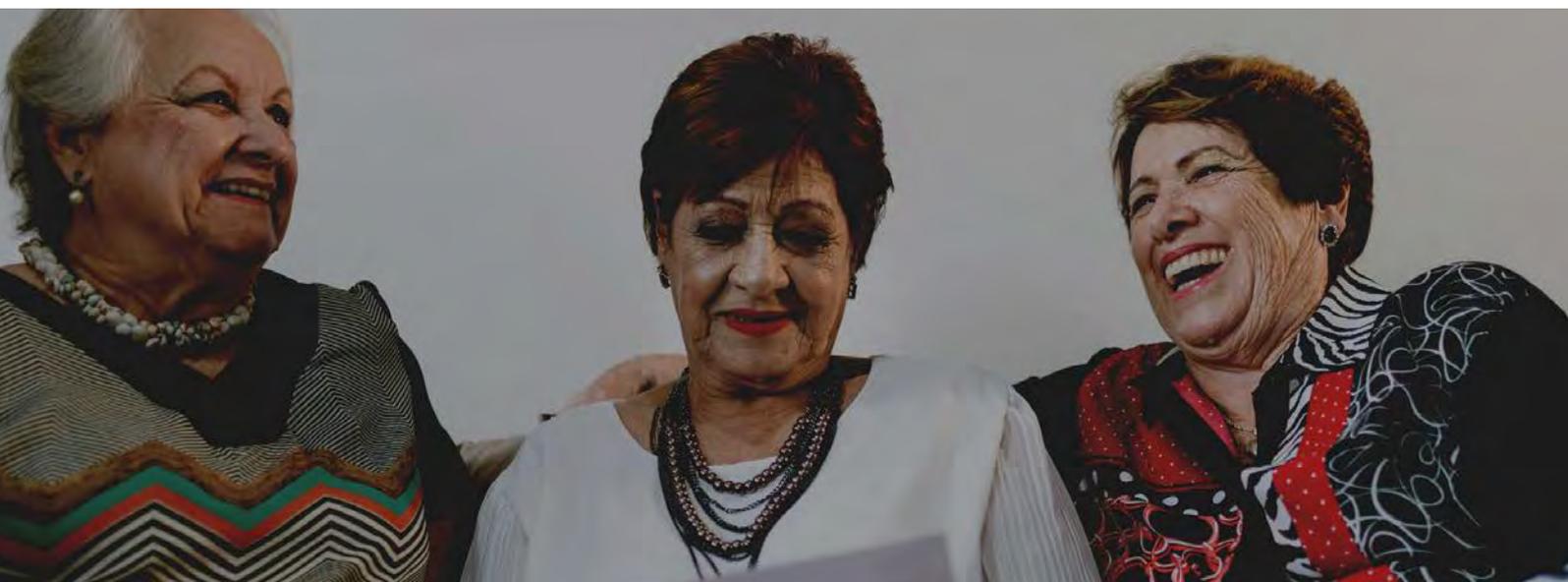
One of the reasons for creating an Advance Care Plan is to provide your loved ones with peace of mind. They will know that you have thought about everything and really know what matters most to you, but they will know you are not going to leave them to make difficult decisions on your behalf.

When discussing the treatments that you do or do not want to receive, the person or people you are speaking with may not feel the same way you do. It is natural for people to ask "why" and for them to want to express their own opinions on matters raised. So try these suggestions to minimise any awkwardness:

- Be clear about what you want to discuss and suggest they spend a bit of time researching the topic so that you can have a productive discussion.
- Ask them to listen first and try to be respectful of your right to make your own decisions about your future.
- Assure them that you will be open to considering all the possible options both in the immediate and long-term future that they might raise.
- Remind them that your plans may change over time but that they will always be an important part of the process and as such, will be kept up to date.

And if you are wanting to talk to someone about their plan, try to do the same things listed above:

- Be clear
- Listen
- Be respectful of people's rights to make their own decisions about their future.
- Assure them that you will be open to considering all the possible options both in the immediate and long-term future that they might raise.
- Remind them that their plans may change over time and they should keep their plan up to date if they change their mind or their circumstances change.



BREAKING THE ICE

So, you've done the groundwork and you now find yourself sitting around the table with your loved ones. How do you get the conversation flowing? Well, there are a number of ways you could try to help break the ice:

The "Direct Approach:

"Right now my health is great, but recent events have shown just how unpredictable life can be and I'd rather you know what I'd want if I fell ill and needed you to make decisions on my behalf."

The "Friend" Approach:

"Do you remember my dear friend Sarah? She ended up on life support after her last stroke. I got the feeling her family argued a lot about it."

The "In the News" Approach:

"Have you seen the news stories about the people in the aged care home affected by COVID-19? They never got to talk to their family about whether they wanted to be intubated or not. I'd hate to be in that situation."

The "Recommendation" Approach:

"I was speaking with my doctor about our family health history and he recommended I consider preparing an Advance Care Plan."

The "This is what happened to me and I don't want it to happen to you" Approach:

"When my mother was frail and old I cared for her and when she suddenly got very sick and went to hospital I couldn't tell the doctors what she wanted them to do because we had never discussed it. That's why I want to let you know what I want you to do for me if I ever get suddenly very sick.

Or - "That's why I want to know what you want me to do for you."





EXPLAINING WHAT MATTERS MOST

At the heart of this conversation, is the need to clearly communicate your wishes for end-of-life care with the people that you love and to those who will be responsible for actioning those wishes if the time comes where you cannot communicate for yourself. Make sure you take the time to discuss why you have made the decisions you have and tell them what matters most to you in regards to ‘quality of life’ versus ‘length of life’.

If you’ve already drafted a copy of an Advance Care Plan, bring it with you to any meetings with a loved one, family member or GP or, alternatively write a list of key points you wish to cover and present them using simple phrases such as:

- “If I require Palliative Care, I would like to go to this location...”
 - “I have thought a lot about what happens if the time comes and I cannot make or voice decisions about my treatment or care. That is why I have decided to appoint this person to be my substitute decision-maker...”
 - “I understand that it might be hard to let me go, but I have decided that I do not want these kinds of life sustaining treatments under any circumstances...”
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THE IMPORTANCE OF SILENCE WHEN LISTENING



To understand more about the importance of silence when sitting besides someone, here's a short video from Touchstone Life Care that includes Dr Michael Barbato, an Australian Palliative Care Physician who sat beside thousands of people as they thought about their own end-of-life:



Dying. Start The Conversation

— “ —

The art of being there is just that - being there. It's not what you can do and what you can say. It's just being there. Nothing to say and nothing to do. Just the space that you create between yourselves.

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