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Start2Talk

INFORMATION AND
WORKSHEETS TO GUIDE YOUR
THINKING AND DISCUSSION IN
PLANNING AHEAD



Start2Talk is a website of Alzheimer's Australia. This booklet – using material from the website – was developed by the Cognitive Decline Partnership Centre to assist all adults to plan ahead.

Introduction

This booklet has been developed from material on the Start2Talk website. The aim is to provide a written resource for people who want to plan ahead either as part of a community group exercise or independently with pen and paper!

If you prefer the flexibility of working on the computer, which can help in making changes in the future or sending copies to family and friends then go to:

START2TALK

visit www.start2talk.org.au today

The 6 easy steps to planning ahead

Planning ahead is not complex or difficult. There are 6 easy steps:

Step 1: Start to think about your future

Step 2: Sort out your financial issues

Step 3: Choose who will speak for you

Step 4: Express your health and care wishes and what is important to you

Step 5: Discuss and share your wishes and plans

Step 6: Review your wishes and plans

This booklet contains a lot of information because it covers all of the aspects of planning. It is suggested you work through these in different sessions or just focus on the ones you feel are most important to you now and you haven't previously completed.

IMPORTANT: Some states and territories have prescribed or recommended forms for Steps 2 (appointing a power of attorney), 3 (appointing a substitute decision maker) and 4 (recording your wishes about health care). You should check for any required documents in your home state or territory by going to www.start2talk.org.au or www.advancecareplanning.org.au.

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Keep control of your future

What is planning ahead?

Planning ahead is thinking about your future, and putting things in place so that your choices will be known and acted on if you cannot express these choices later on in life. This may happen if you have a sudden accident, become very ill or develop a condition like dementia that affects your memory and your planning ability. Planning ahead involves talking to your family and your doctor about what is important to you. It might also involve organising who will make decisions for you if you are not able to.

Why is planning ahead important?

- You still have a say in how decisions are made for you if you can no longer speak for yourself.
- It helps your loved ones if they have to make decisions for you at some time in the future.
- It can give you peace of mind now, because you have told your loved ones your wishes and given both you and them a chance to prepare for the future.
- It is important for everyone, but particularly for people with chronic health conditions or early signs of dementia.

Does planning ahead fit my culture?

- Attitudes to talking about the future and issues such as death and dying can vary between different cultural communities.
- The ways that decisions are made within families and communities can also vary between cultural groups.
- Even if planning ahead does not happen easily in your community, it is still something that can bring benefits for you and your family.

How can I start to plan ahead?

- You can work through all or some of the worksheets in this booklet or go to the website Start2talk.org.au and do the worksheets there.
- Talk to your family about your wishes and show them information from this booklet or the website.
- Talk to your doctor. It may help to take this booklet along and tell them there is information for doctors on the Start2talk website.

What if I cannot understand the material in the booklet or website?

- Check if any family members or friends can explain the material to you.
- If you are part of a social or community group, find out if other members are interested in these issues and if they want to look at the workbook with you. They may also want to do their own at the same time.
- Check if there are any multicultural health or community workers in your area that you may be able to talk to about planning ahead and this booklet or the website.

Step 1: Start to think about your future

Thinking about the possibility of losing capacity to make decisions in the future is confronting for most of us. We often find it difficult to know where to get information and how to start conversations with loved ones about this issue.

Alternatively, we may be ready to discuss what might happen in the future, but the people that we want to talk to about it are not comfortable having the conversation. This may include our family members, close friends, our GP or other healthcare workers.

While these conversations may be difficult to start, many people report that it gets easier once they 'break the ice' and get started. It is also true that people are often relieved to discuss the issues once they have been raised – they had wanted to, but did not know how to get it started. We worry about hurting people by talking openly – but in some circumstances the opposite may be true.

Looking for opportunities to raise the issue

Financial planning around retirement

“Coming up to retirement, we need to review things in our life such as finances and where we will be living. We need to make plans in case one or both of us can't manage our finances. This might also be a good time to think about and make plans for our future healthcare.”

Medical check-ups

“I am due to have my annual check-up. There are a few things worrying me and I would like to discuss these with the doctor and tell him what's important to me about my future care. Can I discuss these with you as well, because you might have to make decisions about my care at some time in the future?”

Death of a friend or relative

“After seeing the negative things that Uncle Jamie went through at the end of his life, I think it is really important for us to talk about what we want for ourselves in the future and do a bit of planning now while we can.”

“It was so good to see that Grandma died in the way she wanted. She knew when she had had enough suffering and she let us and her doctor know ahead of time how far she wanted her treatments to go.”

Movies or news items in the media

“I've just read about the problems families face if a person can't manage their finances and they haven't appointed someone to do this for them. We need to take action now so this doesn't happen to us.”

“It was terrible to watch the suffering that lady went through at the end of her life because nobody knew for certain what she would have wanted. I would hate that to happen to me, so I think we need to talk about what's important to us.”

Having the conversation

There are a number of things we can do to help to get a conversation started.

Prepare for the conversation

- Have some idea of what you want to talk about. It might help to write down your main concerns or questions. You may find it helpful to complete worksheet 1 before you start.
- Have some information that you can give to the other person. It might be something from this booklet or one of the other resources linked on the websites provided.
- Explain why you think it's important to discuss this issue – for both you and them.

Choose the right time and place

- Find a time when you and the person you want to talk with are not distracted or thinking about other things that need to get done.
- Choose a place that is quiet and relaxing.

Have an open and honest conversation

- Raise the subject clearly and confidently so that the other person does not just brush it off. Be prepared to explain why it's important to you and the consequence of not discussing these issues.
- Acknowledge any barriers or difficulties you think the other person may have about having this conversation.
- If the other person is not comfortable talking at the moment, don't force the issue. Give them time to consider it further and ask if they would like to talk about it later.
- Be prepared for them to disagree or feel upset. It's mostly good to get these things into the open and work through them rather than leaving fears or hurt feelings unresolved.
- Be prepared for silences and don't offer reassurance too quickly, as this can close discussion down.

Decide what the next steps are together

- Try to end the conversation with some practical actions. This might be just agreeing to talk again in a week, reading a brochure, following up issues with other people such as their GP or financial adviser, or completing planning sheets.
- Apart from having a conversation, you might want to express your views through writing a letter, making a recording or in some other way.
- You might have a number of small conversations rather than having to have one big, dramatic conversation where everything is discussed.

WORKSHEET 1: Starting the conversation

Why are you interested in planning ahead?

What do you want to get out of doing it?

Talking to family and close friends

Who are the main people you need to have conversations with about planning ahead for yourself?

What are the main issues you would like to discuss in any early conversations?

What would be a good time and place to initiate a conversation about planning ahead?

What are some practical things you need to do in setting up conversations with your loved ones?

Talking to your doctor

What questions do you want to discuss with your GP or Specialist?

Prompt questions might include the following.

- What are my medical conditions/problems?
- How do these affect me now and how are they likely to affect me over time?
- Are there treatment options related to my medical conditions that I may have to make decisions about in the future?
- If I lose capacity to make my own decisions, how will decisions about my care be made?
- What can I do to improve/maintain my health as much as possible?

If you have concerns about memory loss or have a diagnosis of dementia some prompt questions might include the following.

- How will the illness affect my ability to make my own decisions in the future?
- What should I be thinking about now if I am likely to lose capacity in the future?
- Are there support services in the community that would be helpful for me at this stage?

Overcoming difficulties

Are there any reasons why you can't have conversations about planning ahead with your loved ones or your GP?

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What can you do to make these conversations easier?

.....

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Next steps

What further information do you need before going on?

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What is the next step after completing this worksheet?

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Step 2: Sort out your financial issues

This step focuses on the four issues of:

- making a Will
- reviewing your financial resources and plans
- organising your finances so another person can help with their management
- appointing someone to manage your finances on your behalf.

The worksheet at page 12 will help you decide which parts of this Step you might need to do.

Make a Will

A Will is a legal document in which you specify who will inherit your assets when you die. If you die without a Will, your assets will be divided up according to a formula set by the Government. This may not be in line with what you would have wanted. It is also a slow and complicated process, which is stressful for family who have to deal with this.

Get help to make your Will

While it is possible to make your own Will, this can lead to problems later if there are any complications, so get legal help to make your Will. This could be through a private solicitor or trustee, community legal centre or Government service such as a public trustee/advocacy service. You need to have capacity to make a Will – a Statutory or court-authorized Will may be an alternative if this is not the case but you will need legal help for this. Make sure your Will is stored safely and ensure that someone close to you knows where it is kept.

Changing your Will

You can change your Will at any time as long as you have capacity. It is recommended that you review, and possibly change, your Will under the following circumstances:

- marriage, separation, divorce or death of a spouse
- if your children remarry, get divorced or have extended families
- if the executor of the Will becomes ill, dies or is unable to continue being the executor for other reasons
- if a beneficiary of your Will dies
- if you make changes to your financial affairs after you retire
- if you move overseas or interstate
- if you buy or sell significant assets.

Regulations about Wills are fairly standard across Australia with only minor variations across States and Territories. The person who assists you in making a will can advise you on this.

Review your financial resources and plans

Often, we set up financial arrangements but sometimes fail to review these over the years. This might include things such as superannuation, house mortgages, life insurance and financial support of dependent children.

If we lose capacity for whatever reason it will be too late to review these things. Many individuals and their families have suffered because of this. It may be a superannuation policy that had more supportive options that were not chosen; a health insurance policy that does not cover a condition that the person was likely to develop; or an employment, house or life insurance policy that had not been updated.

Financial planning is an important part of planning ahead, especially as a person reaches retirement age. There can be important decisions such as when to retire, selling of assets, pension eligibility or going into a residential aged care facility. You may need to make provision for changing accommodation or care needs, as well as for other people who are still financially dependent on you.

Planning ahead allows you to organise your finances so that you and important people in your life can get maximum benefit from your financial resources with minimal complications.

Organise your finances so another person can help

If a family member becomes too ill to manage their own financial affairs or they lose capacity because of dementia, it can be very difficult for another person to informally manage their affairs for them. Most large organisations have strong policies about privacy and will only talk to the actual account holder. This might be, for example, to make enquiries about a telephone bill, request information from the local Council, move money between bank accounts or get information from Centrelink.

What you can do

- Many couples operate in such a way that one of them tends to manage the finances and often the accounts are in that person's name only. This can make it very difficult for the other person if the account holder can no longer manage that role. One way to reduce such problems is to have accounts in joint names if both parties are in agreement.
- It may also be helpful to organise formally for your partner (or another appropriate person) to be able to make enquiries on your behalf from banks and organisations such as Centrelink.

Appoint a financial decision-maker

Under Power of Attorney regulations, you can legally appoint one or more people to manage your financial affairs.

There are two types of Power of Attorney (POA):

- **General POA:** This is used for specific times such as during an overseas trip or a temporary illness.
- **Enduring POA:** This provides a longer term authority, including situations where the person involved no longer has capacity.

An Enduring Power of Attorney is the best one for people who want to make long-term plans and cover themselves for the possibility of losing capacity to make their own financial decisions in the future.

Who should you appoint?

Appointing someone as your Attorney is a serious matter as the person will be able to manage and make decisions about your financial affairs, to the extent you have specified in their appointment. It is good to let family and friends know whom you have appointed.

- It needs to be someone trustworthy and competent.
- They need to act in your best interest always, keep your money and assets separate from their own and be able to account for how they have managed your money and assets.

- You can appoint more than one person as your Attorney and you can normally specify if they need to act separately or together.
- You can also specify certain conditions such as when the power of attorney will take effect and what types of decisions can be made.

Get legal advice

Because this is a big decision and there are a number of issues that will be relevant to each person's situation, it is recommended that you get legal advice in appointing someone as your Attorney. This could be through a private solicitor, community legal centre or public trustee/advocacy service.

While the general principles underlying Power of Attorney are common across Australia, the forms, terms used, regulations and witnesses required vary among the States and Territories. It is vital that you use the appropriate forms for where you living. There are links on the Start2talk website for more detailed information for each State and Territory.

If you lose capacity to make financial decisions and don't have an appointed Attorney then someone will need to apply to the relevant guardianship board or tribunal to have someone appointed to this role. Attorneys cannot make or change a will on your behalf.

WORKSHEET 2: Organising my finances

Making a Will

Do you have a will?

Yes [] No []

Is it current or do you need to update it?

.....

.....

If you need to update it, how and when will you do this?

.....

.....

What are the main issues you want to update?

.....

.....

Who is the executor named in your Will?

.....

.....

Is this person still the most appropriate person, available and aware they have this role?

.....

.....

Where are your original Will and copies kept?

.....

.....

Who knows where your Will is?

.....

.....

Would there be value in pulling together information for the executor to be able to undertake their role more easily?

.....

.....

Reviewing your financial resources and plans

Are there financial issues that you need to consider and make changes to under the following headings? Tick the boxes that are appropriate for you.

Home mortgage and other debts

Current situation is up to date and appropriate

I need to make changes now. What are these changes?

.....

I am not sure. What information do I need to get to work this out?

.....

.....

Superannuation

Current situation is up to date and appropriate

I need to make changes now. What are these changes?

.....

I am not sure. What information do I need to get to work this out?

.....

.....

Life and other insurances, including benefits and entitlements

Current situation is up to date and appropriate

I need to make changes now. What are these changes?

.....

I am not sure. What information do I need to get to work this out?

.....

.....

Do you need to make plans for financial or other forms of support for adult children or others dependent on you?

.....

.....

Do you need to get the advice of a financial planner to discuss your current and future financial plans?

.....

.....

If so, what are the main issues you need to discuss with a financial planner?

.....
.....

Organising your finances so another person can help with their management

Are there financial or customer accounts that you could make joint accounts by adding another person?

- | | | | |
|--------------------------|-------------|--------------------------|---------------------|
| <input type="checkbox"/> | Bank | <input type="checkbox"/> | Transport authority |
| <input type="checkbox"/> | Electricity | <input type="checkbox"/> | Water rates |
| <input type="checkbox"/> | Gas | <input type="checkbox"/> | Insurances |
| <input type="checkbox"/> | Telephone | <input type="checkbox"/> | Investments |
| <input type="checkbox"/> | Council | <input type="checkbox"/> | Other |

If so, how will you do this?

.....
.....

Do you want to organise for a family member or friend to have the authority to get information or speak on your behalf with any of these organisations?

- | | | | |
|--------------------------|-------------|--------------------------|---------------------|
| <input type="checkbox"/> | Bank | <input type="checkbox"/> | Transport authority |
| <input type="checkbox"/> | Centrelink | <input type="checkbox"/> | Water rates |
| <input type="checkbox"/> | Electricity | <input type="checkbox"/> | Insurances |
| <input type="checkbox"/> | Gas | <input type="checkbox"/> | Investments |
| <input type="checkbox"/> | Telephone | <input type="checkbox"/> | Other |
| <input type="checkbox"/> | Council | | |

If so, how will you do this?

.....
.....

If you are the main person managing financial affairs in your family, what can you do to share that responsibility?

.....
.....

Are the main papers related to your financial affairs up to date and stored together in one place?

.....
.....

Who would know where to find the main papers related to your financial affairs?

.....
.....

Appointing someone to manage your finances on your behalf

What are your reasons for wanting to complete a Power of Attorney?

.....

.....

Do you want to make a General or Enduring Power of Attorney and what are the reasons for this?

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Who will you see to help you complete a Power of Attorney appointment? (e.g. solicitor, community legal centre, public trustee service)

.....

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Do you need to explain to other family members who and why you have appointed a particular person as your Power of Attorney?

You can find out more about Power of Attorney by downloading information sheets and the actual forms for your own State or Territory from the Start2Talk website

Power of Attorney Checklist

There are a number of things you will need to consider when completing a Power of Attorney and you can discuss these with the person who helps you complete the form.

- Which person or persons would be most appropriate to appoint as my attorney?
- Do they have the necessary skills to manage my assets?
- If I appoint more than one person, do I want them to act only together or separately?
- Do I want to make any specific instructions for my attorney to follow?
- When do I want the attorney to start making decisions – immediately or only when I lose capacity?
- How will the attorney decide when I have lost capacity?

Next steps

What further information do you need before going on?

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What is the next step after completing this worksheet?

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Step 3: Choose who will speak for you

This step is about healthcare and lifestyle decisions, rather than financial ones. We generally expect to make our own decisions related to our healthcare and living situation. But what happens if you lose the capacity to make decisions – either because of an accident, sudden illness or a progressive illness like dementia? Identifying and possibly appointing someone who will make decisions on your behalf is an important part of planning ahead.

Determining who would make healthcare decisions for you can happen either:

- according to definitions in legislation within each State or Territory, or
- by you legally appointing someone to be your substitute decision-maker for healthcare decisions.

Your decision-maker: Persons identified in state and territory legislation

The term and definition used for your decision-maker varies across the States and Territories but common terms include:

- Person Responsible
- Statutory Health Authority
- Treatment Hierarchy.

These definitions will typically involve categories of people (e.g. guardian, spouse, informal carer or parent) that a doctor must approach to get consent for any proposed treatment if you cannot give your own consent. Information about the specific definitions for each State and Territory can be found on the Start2Talk website.

Is this the person you would have chosen for yourself?

In many cases, the person identified like this in legislation is the same person that you would have chosen yourself. But this is not always the case.

Some situations where it is not so clear cut are when a person has:

- nobody in their life close enough to be able to make decisions for them
- family members that they have no real connection with
- a family characterised by disagreement and conflict
- concerns that their identified person might not want to take on this role
- concerns that their identified person might not make the decisions they would make for themselves if they still had capacity
- concerns that the identified person may not have the skills, temperament or experience to take on this role
- somebody they want to make decisions for them that is not recognised by others in the person's life e.g. a de facto or same-sex partner

Legally appointing your decision-maker

If you have any concerns that the person who would be asked to make future decisions on your behalf will not be the person you would have wanted, then you can act now and legally appoint your preferred person. This will give you peace of mind that any decisions will be made by someone you have confidence in. A person appointed by you as your substitute decision-maker for healthcare only takes on this role if you lose capacity to make your own decisions. They do not have the power to manage your financial affairs – unless they have also been appointed separately to take that role.

While the general principles underlying legal appointment of a substitute decision-maker for healthcare are similar across Australia, the terms used, regulations and witnesses required vary among the States and Territories. For example, in some states a decision-maker appointed by you for personal and/or health care decisions is called an Enduring Guardian, in others an Enduring Power of Attorney – Personal/Health Care or Agent EPOA (Medical Treatment). It is vital that you use the appropriate forms for where you living. See the Start2Talk or Advance Care Planning websites for more detailed information from each State and Territory.

Guidelines for choosing your decision-maker

This is a very important role and something you should consider carefully. It is important that the person you choose:

- meets the legal criteria in your State for acting as agent or proxy or representative
- would be willing to speak on your behalf
- would be able to act on your wishes and separate his/her own feelings from yours
- lives close by or could travel to be at your side if needed
- knows you well and understands what's important to you
- is someone you trust with your life
- will talk with you now about sensitive issues and will listen to your wishes
- will likely be available long into the future
- would be able to handle conflicting opinions between family members, friends, and medical personnel
- can be a strong advocate for you in the face of an unresponsive doctor or institution.

Supporting and empowering your substitute decision-maker

You can do a lot to help your substitute decision-maker perform their role confidently and effectively.

- Make sure they are doing it willingly.
- Ensure they understand what the role entails.
- Discuss your values and views about your future care.
- Make sure they have a reasonable understanding of your health conditions, and health choices that may need to be made in the future.
- Ensure they are clear on the issues they need to address when advocating on your behalf.
- Make sure they have copies of any relevant documents related to your wishes.
- Ensure they know how and when to step in as a substitute decision-maker.

Think about other people in your life who may expect to have a say in your care, explain to them who you have appointed and why, and ask these people to support the person you have appointed if you think this may be an issue.

WORKSHEET 3: Who will be my spokesperson on healthcare issues?

1. If you were in a situation where you did not have the capacity to make your own decisions about medical treatment, who would you want to make decisions for you? (i.e. to consent to, or refuse, specific treatments)

.....

.....

2. According to regulations in your State or Territory who would your doctors ask for consent for your medical treatment? (*Information about this is available under the State/Territory section of www.start2talk.org.au*)

.....

.....

Is the person in Question 2 the same as you have nominated in Question 1?
Yes [] No []

If the answer is No, you should definitely consider appointing your preferred person as your legal substitute decision-maker. Even if the answer is Yes, you could still consider appointing your preferred person as your legal substitute decision-maker as there are advantages to this.

- It gives the person a stronger legal basis to act on your behalf.
- It allows them to act with more confidence knowing you have specifically asked them to take on this role.
- It gives you peace of mind knowing there is clarity in who will make decisions on your behalf, and
- It reduces the likelihood of uncertainty and conflict amongst family and friends who are concerned about your care.

Legally appointing a substitute decision-maker

Do you want to legally appoint someone as your substitute decision-maker?
Yes [] No []

(You can find out more about appointing someone to make healthcare decisions for you by downloading information sheets and the actual forms for your own State or Territory from the Start2talk website)

Who will you see to help you complete the required legal form? (e.g. solicitor, community legal centre, public trustee service)

.....

.....

Decision-maker checklist

- There are a number of things to consider when completing this kind of legal form and you can discuss these with the person who helps you complete the form. You may want to print out this checklist and make notes on it:
- Who is the best person or persons to appoint?
 - Would they be willing to speak on your behalf?
 - Would they be able to act on your wishes and separate his/her own feelings from yours?
 - Do they live close by or could they travel to be with you if needed?
 - Do they know you well and understand what's important to you?
 - Are they someone you trust with your life?
 - Will they talk with you now about sensitive issues and listen to your wishes?
 - Are they likely to be available long into the future?
 - Would they be able to handle conflicting opinions between family members, friends, and medical personnel?
 - Would they be a strong advocate in the face of an unresponsive doctor or institution?
- How many people do you want to appoint?
- Does the application form in your State/Territory require or allow you to select specific areas to make decisions on e.g. surgery / accommodation etc
- Does the application allow you to give specific directions to the person(s) you are appointing about how they should make decisions for you?

If you appoint one or more people, will this cause friction with other people in your life? If so, is there anything you can do now to reduce this?

.....

.....

Are there other people you would like the substitute decision-maker to consult with about your care?

.....

.....

Have you prepared any kind of advance care plan or directive that you want your substitute decision-maker to follow?

Yes [] No []

If so, do they have copies and understand how to use these documents?

Yes [] No []

If you haven't prepared any advance care plans or directives, what are the really important issues that you want your substitute decision-maker to consider when making decisions for you?

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Next steps

What further information do you need before going on?

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What is the next step after completing this worksheet?

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Step 4: Express your health and care wishes

Like Step 3, this step focuses on lifestyle and healthcare decisions, rather than financial ones. The issues discussed in both these steps are commonly referred to as 'advance care planning'.

What is advance care planning?

This is the process of thinking about and communicating your values, beliefs and preferences so that these can guide decision-making if you cannot make decisions for yourself at some time in the future. In this case, someone else has to act as your substitute decision-maker. This may happen if you have a sudden illness or gradually lose capacity from an illness such as dementia.

Levels of formality

There can be varying levels of formality involved in advance care planning. Ranging from most to least formal, the options include:

- completing a statutory advance care directive (established in legislation) in which you give instructions about future healthcare treatments, if such a directive is available in your State or Territory
- legally appointing another person to be able to make healthcare and/or lifestyle decisions for you if are not able to do this for yourself, and giving this person instructions on how to make decisions on your behalf
- completing a directive recognised under common law that may give directions about consent for, or refusal of, specific treatments and/or include a general statement of values, wishes and preferences to guide substitute decision-makers
- having one or more conversations about things that are important to you with family members, your GP or other persons.

Benefits of a more formal approach

The benefit of taking a more formal approach is that your wishes can be stated more clearly and they are more likely to be seen as having a legal basis. Furthermore, if you have appointed a substitute decision-maker and also given them clear and formal instructions, that person will feel more confident about advocating strongly on your behalf if there is uncertainty or disagreement about certain decisions.

Attitudes to advance care planning

Individuals may have various attitudes about advance care planning.

- Some people may not feel the need to express their values, beliefs and preferences because they feel that family and loved ones will understand these anyway when making substitute decisions for them.
- Some people may want to explain what values, beliefs and preferences are important to them, but they are happy for their family or loved ones to make substitute decisions on their behalf about specific treatments.
- Some people will want substitute decision-makers to consider their values, beliefs and preferences in any decisions they make on their behalf, but they also want to

give instructions about specific treatments they would, and would not, consent to in the future.

Guidelines for completing the advance care worksheets

- You may choose to work through the worksheets on the next pages on your own or you might want to discuss them with people close to you.
- If you feel that some of the questions are not relevant to you, leave them for the moment and move on to other questions.
- You may want to write your answers to the questions or use them to provide some structure to a conversation about your values and wishes.
- As with other worksheets in this booklet, you can complete them here or go to the Start2talk website where you can save a Word version to your computer so that you can complete, make changes at any time and print out the completed worksheet.
- When you complete each worksheet in this section, you should sign and date it, and have at least one person witness your signature. This person should also provide their contact details. Although there is no specific legal requirement for this, it is a sensible thing to do in case there is any doubt in the future about the validity of the document.
- The questions presented in these work sheets represent one example of an advance care planning format. There are a number of other formats available from other programs and these are listed in the resources section of the Start2Talk website.

Giving instructions about specific treatment choices

- If you want to give instructions about specific treatments, it is important to be well-informed about your own health and about the treatments you are specifying in your directives.
- You need to be clear about the situations and circumstances in which you expect your directives to be implemented e.g. if you are in a terminal state of a disease, or if your condition is reversible or irreversible.
- While not strictly necessary, it is a very good idea if you are able to discuss your situation and choices with your GP and other treating doctors. This is to make sure you have all the relevant information; it is also to make sure they are aware of your directives and are prepared to follow them. It is also helpful if there is any doubt in the future about the validity of the document.

State and Territory-based statutory advance care directives

- There is no one Australia-wide advance care directive established by legislation.
- The statutory directives that do exist have been established by legislation in various States and Territories. They exist in all States/Territories except Tasmania and New South Wales.
- They vary in terms of how they are constructed and what issues they cover.
- When statutory directives are available in a State or Territory, it is recommended to use them, as they will have a clearer legal basis than other forms of directives (referred to as 'common law directives').

If you want to complete one of these forms, it is essential to use the processes and forms for your particular State or Territory. Use the State and Territory links at the website Start2talk.org.au to get information about documenting your wishes relevant to your State/Territory, including downloading copies of the statutory directive.

It is not always clear how well a directive from one State or Territory will be recognised in other locations. If you move to a new State or Territory and plan to stay there for some time, it is a good idea to complete a directive from that particular State or Territory, if one is available.

- If you have already lost capacity, completing new legal forms if you move interstate may be difficult. You may need to seek guidance on this issue from the guardianship office in your State or Territory.

Choosing which document to complete

You can choose to complete one, two or three of the following options.

Complete Worksheet 4a: General statement about values, wishes and preferences – if you only want to provide **guidance** to help others make decisions that reflect your wishes.

Complete Worksheet 4b: Advance care directions about specific treatments – if you want to give **clear indications** about what treatments you would or would not consent to.

Complete a statutory advance directive if one is available in your State/Territory.

These allow you to set out your directive in a way that complies with local legislative requirements. These are available through the State and Territory links on the Start2talk.org.au website.

WORKSHEET 4A: General statement about values, wishes and preferences

IMPORTANT: WHERE THERE IS A LEGISLATED FORM IN YOUR STATE/TERRITORY USE THAT FORM INSTEAD – this worksheet can guide your thinking ahead of completing that form if you wish.

Name: Date of birth:

Address:

This statement sets out many of the issues that are important to how I want to live my life and how I want to be cared for by others. I am making this statement willingly because there may be some time in the future when I am unable to express these things myself, because of illness or injury. If this situation occurs, I want my substitute decision-maker(s) to make decisions about my care based on my values, wishes and preferences as expressed here.

(If there are statements below that you do not wish to answer or you feel are not relevant to you then you can cross them out to show this.)

Substitute decision-makers

Have you legally appointed someone to make healthcare decisions on your behalf if you are not able to make your own decisions (such as an Enduring Guardian or Medical Power of Attorney)?

Yes [] No []

The name and contact details of this person or persons are:

.....
.....

If you have not legally appointed someone, who are the person or persons you would want to make decisions for you and what are their contact details?

.....
.....

Do you have other people that you would like to be included in discussions about your care?

Yes [] No []

If yes, what are their names and contact details

.....
.....

Health

Do you have significant health problems now and, if so, how do these affect you?

.....
.....

How do you expect your health problems will affect you in the future?

.....
.....

Is it important to you to have specific doctor(s)/other healthworker(s) looking after you?

Yes [] No []

If Yes, name the healthcare professionals you prefer:

.....
.....

Would you like to receive alternative medicines/treatments and have this respected? If so, what are these?

.....
.....

In terms of receiving information about your prognosis and care, do you want to be told as much as possible or just the basics?

.....
.....

Concerns and fears

Do you have concerns or fears about the possibility of losing capacity (not being able to make your own decisions) at some time in the future?

.....
.....

Is there anything else in particular you are worried about regarding the future?

.....
.....

Life values

What roles do family and friends play in your life?

.....
.....

Do you have religious, spiritual or lifestyle beliefs that are important to you and that you want others to acknowledge and respect? How might these influence the care you want to receive?

Are there aspects of your sexual orientation or identity that you want others to acknowledge and respect? How might these influence the care you want to receive?

What are the most important thing(s) that you want medical and other staff that are looking after you to know about you?

What are the qualities of medical and other staff that may be looking after you that are most important to you?

Quality of life

What activities would you like to do/keep doing even when you cannot request that any more?

Do you have views about the possibility of having intimate and sexual relationships if you get to a point where you lose capacity to request this?

Do you have any unfinished business that you would like to attend to while you can? This may include relationship breakdowns, unresolved disagreements, telling someone you love them etc.

On receiving community and residential care

If you become unwell and need support to stay at home, what are the main things you would want staff looking after you to be aware of about you/your feelings/your attitudes to receiving care?

If you were living at home, at what point would you accept the need to go into residential care? This may include physical health, safety, support available and impact on your family of trying to care for you etc.

If you do have to go into residential care, what are the things that would be really important to you? This may include:

- location of home
- size of home
- single room
- music
- visitors
- going out
- types of activities
- food
- touch
- sexual expression
- cultural aspects of care
- spiritual aspects of care

On care toward the end of life

Have you seen anyone else's end-of-life experiences that you would either want for yourself or wish to avoid? If so, can you describe these?

Do you have concerns or fears about dying? If so, can you describe these?

In terms of your views about your quality of life in the future, at what point would you want the goals of medical care to switch from intensive treatments aimed at prolonging life to focusing on palliative or comfort care? Some people describe this in terms such as the irreversible loss of ability to recognise people, feed themselves, walk, talk etc.

How do you compare the importance of living as long as possible, no matter what, to having a good quality of life at the end?

.....

.....

What would be an ideal death for you? Consider issues such as your environment/people around you/comfort/pain relief etc.

.....

.....

Do you have any views or preferences about where you are cared for at the end of life? For example, hospital/ home/ hospice. This statement is made with an awareness that where you are cared for will depend on the support and resources available at the time.

.....

.....

What would you need for comfort and support as you journey towards death?

This may include

- prayer
- family
- clergy
- music
- physical touch etc.

.....

.....

If you are approaching death and cannot communicate, are there things you would like family/friends to know?

.....

.....

On organ and tissue donation

My attitude to organ and tissue donation is that

I consent

I do not consent to donation

Have you made your wishes known through the Australian Organ Donor Register?

Yes No

(For more information, visit www.donatelife.gov.au website)

Have you made your wishes about organ donation clearly known to your family, who will have to give final consent for this procedure?

Yes No

On funeral arrangements

Have you made a Funeral Plan?

Yes [] No []

If yes, where are the documents held?

.....

.....

In terms of burial or cremation, what is your choice?

[] I definitely want to be buried

[] I definitely want to be cremated

[] I am happy to be either buried or cremated

Would you like to have some input to how your funeral is organised?

Yes [] No []

If Yes, what would you like to see happen?

.....

.....

Next step

Which of the following two options do you choose?

1. I am happy for my substitute decision-makers to use the information here to make any treatment decisions in the future on my behalf?

OR

2. I want my substitute decision-makers to consider this information in any decisions they make on my behalf, but I also want to give directions about treatment options in the future, which I expect to be followed.

If you choose Option 1, complete this Work sheet according to the instructions below.

If you choose Option 2, complete this worksheet according to the instructions below and then progress to complete Worksheet 4b: Advance care directions about specific treatments.

If you complete this worksheet, it is strongly recommended that you sign and date it as well as have at least one person witness your signature. They should also provide their contact details. Although there is no specific legal requirement for this, it is a good practice in case there is any doubt in the future about the validity of the document.

Your Signature: Date:

Witness 1:

Name: Signature: Date:

Address:

Phone number:

Witness 2:

Name: Signature: Date:

Address:

Phone number:

Dates this Work sheet was reviewed by person completing it to check its currency:

Signature: Date:

Signature: Date:

Signature: Date:

WORKSHEET 4B: Advance care directions about specific treatments

IMPORTANT: WHERE THERE IS A LEGISLATED FORM IN YOUR STATE/TERRITORY USE THAT FORM INSTEAD – this worksheet can guide your thinking ahead of completing that form if you wish.

Name: Date of birth:

Address:

This statement sets out clearly what treatments I would, and would not, consent to under the conditions outlined below. I am making this statement willingly because there may be some time in the future when I am unable to express these things myself, because of illness or injury. If this situation occurs, I want my substitute decision-makers and any treating doctors to respect my wishes and follow the directions I have given. I accept that some of the treatments listed below may be considered medically futile in end-stage disease and may not be offered as a treatment option.

(If there are statements below that you do not wish to answer or you feel are not relevant to you then you can cross them out to show this.)

In terms of your views about your quality of life in the future, at what point would you want the goals of medical care to switch from intensive treatments aimed at prolonging life to focusing on palliative or comfort care? Some people describe this in terms such as the irreversible loss of ability to recognise people, feed themselves, walk, talk etc.

.....
.....
.....

If you reach that point in the future where:

- your quality of life is very low as defined in the previous question;
- your underlying medical condition is irreversible, i.e. it will not get better;
- you are not able to express your wishes at the time;

AND

a) Your heart suddenly stopped, would you consent to having cardiopulmonary resuscitation (CPR) and life support (including defibrillation to restart your heart or putting a tube into your lungs to support your breathing?)

Yes [] No []

b) You could no longer safely take food or fluid by mouth, would you consent to being fed indefinitely by a tube into your stomach?

Yes [] No []

c) You were unconscious and unable to breathe on your own, would you consent to being supported indefinitely on a mechanical ventilator?

Yes [] No []

d) You developed renal failure, would you consent to being supported indefinitely by kidney dialysis?

Yes [] No []

e) Your medical condition deteriorated, would you want treatments that primarily focused on providing comfort and dignity rather than treatments that primarily focused on extending your life at any cost?

Yes [] No []

f) If any of the above interventions have been commenced but there is no chance that your quality of life as defined above will improve, would you consent to the interventions being stopped?

Yes [] No []

g) Are there any of the above – or any other – medical treatments that you would definitely refuse under all circumstances? If so, what are these?

.....
.....
.....

Are there any other directions you want to give to medical and other staff that may be looking after you at the end of life?

.....
.....
.....

If you complete this worksheet it is strongly recommended that you sign and date it as well as have at least one person witness your signature. They should also provide their contact details. Although there is no specific legal requirement for this, it is a good practice if one witness can be a medical doctor. This is partly to make sure you have all the relevant information; it is also to make sure they are aware of your directives and are prepared to follow them. It is also helpful if there is any doubt in the future about the validity of the document.

Signature of person completing form: Date:

Witness 1:

Name: Signature: Date:

Address:

Phone number:

Witness 2:

Name: Signature: Date:

Address:

Phone number:

Dates this worksheet was reviewed by person completing it to check its currency:

Signature: Date:

Signature: Date:

Signature: Date:

Step 5: Discuss and share your wishes and plans

Having completed the worksheets in this booklet, or any other form of written advance care plan, it is really important to let other people know about this. It won't help you if these documents are stored away at your home or your solicitor's office and nobody knows about them or where to find them when they are needed.

You need to have conversations about your wishes and your written documents with people who may be called on to make decisions for you (your substitute decision-makers). They will be able to advocate more strongly and confidently on your behalf if they have your written documents and are clear about the meaning and purpose of these.

Guidelines for discussing and sharing your plans

- Complete the worksheets and any other paperwork as fully as possible. Check that you follow any special conditions, such as the need for witnesses to sign your documents.
- Keep the originals of any documents in a place where you and others can find them easily.
- Identify any people you have appointed as legal substitute decision-makers as well as people who would take on that role informally if needed.
- Set aside times to talk to each of these people to explain what you have done and what you want them to do if they ever have to make decisions for you.
- Leave copies of your documents with each of these people.
- Make sure they are comfortable with your expectations. They may need time and support to accept the idea of advance care planning. If they are still not comfortable after further discussion, you may have to ask somebody else to take this role.
- Give copies of your documents to your GP and ask for them to be included in your records. If the GP is not supportive of what you are doing, you may need to discuss this further or consider transferring to another GP.
- If you are going to hospital or an aged care facility, take the documents with you and ask for them to be included with your records.
- Carry a card in your wallet or purse that has the name and contact details of your substitute decision-maker and location of any advance care planning documents. There is a suggested template for you to complete later in this booklet.

If possible, have a number of **certified copies** of documents (e.g. by a Justice of the Peace) as these may be required by some organisations.

Talking about your decisions

Many people will be happy and comfortable to talk with you about advance care planning and healthcare issues. If this is not the case, there are a number of things you might do to help to get a conversation started.

- Find a time when you and the person you want to talk with are not distracted or thinking about other things that need to get done.
- Choose a place that is quiet and relaxing.
- Be clear in your own mind what you want to achieve out of the conversation.

- Explain why you think it's important to discuss this issue – for both you and them.
- Acknowledge any difficulties they may have and allow them to express their concerns or uncertainties.
- If the other person is not comfortable talking at the moment, don't force the issue. Ask if they would like to talk about it later.
- You might have a number of small conversations rather than having one big, dramatic conversation where everything is discussed.
- If you are a bit unsure how the conversation will go, you could practise with a friend or health professional first to increase your confidence.

WORKSHEET 5: Communicating my wishes to others

Who are the main people you need to talk to about your worksheets or other documents? These would normally be people who may end up as substitute decision-makers for you.

.....

.....

What are the key issues you want to get across in conversations with these people?

.....

.....

.....

What are key issues you want to get across to your GP or other treating doctors?

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.....

.....

Overcoming barriers

Are there likely to be barriers to you having these conversations with your substitute decision-makers or doctors?

.....

.....

.....

If so, how can you overcome these barriers?

.....

.....

.....

Where will you keep copies of your worksheets and other documents?

.....

.....

Who do you need to give copies of your worksheets and other documents?

.....

.....

.....

Are there other people (such as neighbours or friends) who should be told who your substitute decision-makers are? This may be useful for emergency contacts.

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.....

Next steps

What further information do you need before going on?

.....

.....

What is the next step after completing this worksheet?

.....

.....

Step 6: Review your wishes and plans

Planning ahead is not a single event that happens once. It is more like a series of discussions and actions, an ongoing conversation over time. Your health, family and social circumstances – and possibly your attitudes and preferences – will change as you go through life and it is important that any plans you make reflect these changes.

Benefits of reviewing your plans

Reviewing your plans gives you a chance to keep open communication about these issues with important people in your life. It is also helpful if medical or other staff are worried about the currency of any documented wishes. It will make them feel more confident if they can see that you have revised, initialled and dated them at different times.

When should you review your plans?

Reviewing your plans and any written documents can occur on a regular basis as well as when circumstances change. You may choose to review your plans regularly each year or two around your birthday, an annual medical check-up or around New Year.

Circumstances that might prompt you to review your plans can include:

- diagnosis of a new health condition
- significant deterioration in an existing health condition
- reduction in your ability to live independently
- changes in support structures around you – such as divorce or death of a spouse
- people you expected to be your substitute decision-makers not being able to do this anymore.

Guidelines for reviewing your plan

- For all documents related to planning ahead, make sure you keep them in a secure place where you can find them easily and they can be located by someone who may become your substitute decision-maker.
- Decide on a time when it would be good to review these documents on a regular basis e.g. at an annual medical check-up, around your birthday, at New Year or when doing your tax return.
- Be aware of other changes in your circumstances, such as a change in your health status that may prompt a review of your planning documents.
- If you are using formal documents such as Enduring Guardian appointment or statutory Advance Care Directive, check any specific requirements that might be required for reviewing or updating these documents, e.g. the type of witness or the need to complete a new form.
- After any review you may be happy to leave documents as they are, or you may need to write new ones. If you leave them as they are, indicate this on the form by initialling them with the date. This will show the currency of your wishes to people who may need to use the documents.
- If you have given people verbal instructions about your wishes and you change your mind about these wishes, make sure you contact these people and explain your current views.
- If you have given people copies of documents related to planning ahead and you update or change these, make sure you contact the people, ask them to destroy old

documents and online files and give them current copies of documents and electronic files.

Information card

To slip into your wallet or purse in case of emergencies

IN CASE OF EMERGENCY	
My Name:	
My date of birth:	
Substitute decision maker to contact about my care:	
Name:	Contact:
Name:	Contact:
My allergies/significant medical conditions:	
PLANS OR DIRECTIVES ABOUT MY HEALTH CARE	
I have written plans or directives for how I want decisions to be made for me if I cannot speak for myself:	
Yes <input type="checkbox"/> No <input type="checkbox"/>	
If Yes, please get a copy of these from:	
Name:	Contact:
Name:	Contact:

You can complete, cut out and fold (with printing to the outside) and slip into your purse or wallet. This will ensure important information is available should you be involved in an accident or other emergency and can't talk to those providing assistance.

For more information:

- More information, including worksheets to help others plan ahead is available at www.start2talk.org.au
- General information on advance care planning is also available at: www.advancecareplanning.org.au

Both of these websites provide links to information and resources available for each state and territory, including any statutory or required forms. They both also have a lot of other helpful information.

A helpful guide giving further information about the legal basis for advance care planning and decision-making, particularly for those with dementia or other cognitive decline is available at:

<https://www.fightdementia.org.au/sites/default/files/NATIONAL/documents/Dementia-and-your-legal-rights.pdf>

Development of the booklet

Research undertaken by the Cognitive Decline Partnership Centre found that advance care planning (ACP) can provide many benefits, including receiving care in line with one's wishes and reducing the stress on families. The report recommended that planning ahead including advance care planning be promoted for all adults, especially people over 50. This booklet was developed as part of implementing some of the report's recommendations. It builds on the work of Alzheimer's Australia to provide a mechanism for all adults to undertake planning ahead covering a wide range of issues.

The report is available at

<http://sydney.edu.au/medicine/cdpc/resources/advance-planning.php>

Our thanks also go to the consumers who provided insightful comments on the format and content of the booklet.