

Planning Ahead

An information guide
for older people
and their families
in South Australia



ACH GROUP

ACH Group is dedicated to creating opportunities for older people to thrive. We believe growing older is akin to turning a new page and with it comes a sense of great anticipation and optimism.

Our focus on innovation and services that respond to changing needs reflects our desire to shift the way the community thinks about older people.

ACH Group's 1700 specialist staff and hundreds of volunteers share our belief that older people should be valued and respected, connected to their communities and in control of their lives. This mindset drives our every action to empower older people, to support them to lead a good life and continue to make a contribution to family, community and society.



For more information about ACH Group services please call 1300 22 44 77 or visit the website www.ach.org.au

© 2015 ACH Group. Reviewed July 2016
ISBN: [978-0-9806199-6-6]

All rights reserved. Except under the conditions described in the Copyright Act 1968 of Australia and subsequent amendments, no part of this publication may be reproduced, stored in a retrieval system or transmitted in any form or by any means, electronic, mechanical, photocopying, recording or otherwise without the prior permission of the copyright owner.

Whilst every effort has been made to ensure the accuracy of this guide, the author cannot accept or assume any responsibility or legal liability for its use, including liability for negligence, for errors or oversights in the information provided.

This material is general in nature and gives an overview of advance planning issues for older people and their families and will not provide ALL the information needed on this topic. Independent professional advice should be sought about specific issues.

The project team was Lenore de la Perrelle, Manager of the Dementia Learning and Development Unit, ACH Group, and Project Officers, Kelly Quinlan and Teresa Moran. Produced and Printed in South Australia.

CONTENTS

Introduction	4
FOR INDIVIDUALS	7
Lifestyle and medical decisions	12
Financial decisions	18
FOR FAMILIES	19
Planning for a good life	20
Planning ahead... for greater peace of mind	24
Lifestyle and medical decisions	28
Financial decisions	32
Towards end of life... comfort and dignity	34
Planning for a good life... last words	38
USEFUL CONTACTS	39
More information?	42
Planning Ahead checklist	50



If you wish to contact ACH Group through the use of an interpreter, please contact the **Translating and Interpreting Service (TIS)** on 131 450

INTRODUCTION

This guide was developed by ACH Group to help people with future planning and to give clear information to assist with it.

This guide is to help you plan for a full life and continue to make a contribution to family, community and society as you age. It is a guide about the important decisions that affect your quality of life right through to the end of life.

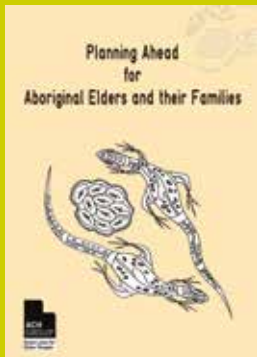
The guide is in three sections:

- **For individuals** - this first section is written for you
- **For Families** - this second section is for family members* who you speak with about planning ahead issues
- **More Information** - this section at the back of the guide lists key organisations that can help you with further information and support.

You may want to read the whole booklet to understand what is involved or read only the sections that interest you. A **checklist** (see page 50) at the back of this booklet can be used to help you with decision-making steps along the way.

We spoke to older people and their family members about their experiences and all names associated with any quotes have been changed to respect privacy. We sincerely thank everyone who contributed generously to the development of the guide and for sharing their experiences and wisdom.

* Anyone in close association with the older person can be regarded as a 'family member' regardless of whether or not they are related. In this guide 'family member' and 'relative' are used interchangeably.



Planning Ahead for Aboriginal Elders and their families

The information included in this guide is relevant to Aboriginal Elders and their family members.

An accompanying DVD was developed in 2011 and updated in 2016 to complement this and to encourage conversations about planning ahead issues in Aboriginal communities.



For Individuals

TAKING CONTROL

IN THIS CHAPTER

Planning for a good life... taking control	8
Lifestyle and medical decisions	12
Financial decisions	18

Planning for a good life... taking control

Ageing may bring changes to the life you planned. You might need to think about what's important to you and make changes to manage any physical, mental or emotional matters. It is hard for any of us to know what the future holds, so it is important to have control over the decisions in your life. Planning ahead gives you a say in your future and helps you to live more positively.

Planning ahead... for greater peace of mind

Planning ahead helps to inform what happens to you in the future if you can't make decisions for yourself or aren't able to communicate your wishes.

Thinking ahead about future decisions as early as possible allows you to stop worrying and live well. You can choose to:

- tell people close to you about what you want
- choose people to make decisions for you in the future
- write down your preferences
- do nothing and leave decisions to your family or the government.

Telling people your wishes

Talk with your family about the things that are important to you, give you pleasure and add meaning to your life. This will help them to respect your wishes in the future when deciding about your lifestyle, care and treatment, including:

- hobbies and interests that you want to continue
- use of services and caring arrangements
- the management of your financial matters
- religious and cultural practices which are important to you
- medical treatment and end of life.

Appointing people

You can choose people you trust to make decisions for you in the future – a ‘Substitute Decision Maker’. The people you choose need to know your wishes. To do this you need to complete legal forms called Advance Directives.

It is a good idea for every adult to make these directives as life is uncertain for us all.

An Advance Care Directive allows you to:

- Write down your wishes, choices and instructions for future care, where you want to live, personal matters and end of life
- Choose one or more people to make decisions for you if you can’t in the future. If more than one person, you can decide whether they make decisions by themselves or together.

An Advance Care Directive cannot be used to make financial or legal decisions*. You need to be able to show that you understand what the Advance Care Directive is about and the end result of the decisions you are making. This is called decision-making capacity.

All documents must be witnessed by an authorised witness.

It’s a good idea to:

- keep these documents in a safe place
- let someone know where they are kept
- give copies to those who will have responsibility for making decisions for you.

Check your Advance Care Directive often and if your wishes or situation changes. Let family members know of these changes.

* A separate document needs to be done for this called an Enduring Power of Attorney

‘You need to know about the power you’re giving someone.’

{Jenny, family member}

Writing down your preferences

You can write down a simple description of what is important to you or give more detail about what you want done in a certain situation. This can then be given to the people you have chosen to make decisions for you. You can change your instructions anytime while you still have decision-making capacity.

Who can help with Advance Care Directives?

Legal issues can be confusing. You can get information and advice from the Office of the Public Advocate and the Legal Services Commission (see Planning Ahead, page 45-46). You can also discuss things with:

- your family members and close friends
- your doctor
- a community care or aged care provider like ACH Group
- your financial advisor
- your solicitor.

The Advance Care Directive can be done:

- online at www.advancecaredirectives.sa.gov.au
- yourself with a Do it Yourself Kit
- with the help of a solicitor or a trustee company.

Doing nothing

By law, family members can make simple decisions about finances and some lifestyle and medical treatment decisions. A relative may already be:

- a nominee for you for Centrelink
- a signatory on your bank accounts
- organising services for you
- agreeing (giving consent) to your medical and dental treatment.

If you have not talked about or written down your choices, your relative may be confused about what you would want done in certain situations.

These arrangements can continue after you lose the ability to make decisions unless:

- there is a disagreement about the decisions being made
- your financial affairs are complex
- there is a need to sell property
- there is a need to refuse medical treatment.

When this happens, or if you don't have a family member or friend to make decisions for you, someone may be legally appointed by the South Australian Civil and Administrative Tribunal (SACAT). If you do nothing about your arrangements, it is possible that this will happen and the end result may be different than if you were deciding for yourself or have chosen someone to do it for you.

● ● ● **More information? See Planning Ahead page 47.**

'My parents believed that it was not fair to leave the family to make the decisions. They considered that it is your responsibility as an adult to make those things clear. This made life much easier for me. That discussion very early is important so that people are clear.'

(Pam, family member)



Lifestyle and medical decisions

Advance Care Directive – lifestyle and medical decisions

An Advance Care Directive lets you choose someone to 'speak' for you about future medical care and treatment decisions. You can write down your wishes about personal matters, medical care and treatment at the end of life. In South Australia, laws changed from 1 July 2014 and Advance Care Directives are now in place. If you have an Enduring Power of Guardianship and/or Medical Power of Attorney or an Anticipatory Direction they are still legally recognised.

Lifestyle decisions

Staying healthy and active

Being involved in physical, mental and social activities is important. There is a lot you can do to stay as healthy, active and independent as possible. Doing things around the home and activities in the community can:

- give you enjoyment and pleasure
- let you stay in touch with friends and your local community
- help keep your existing skills, abilities and level of independence
- increase your confidence and your well-being
- give you control over your life
- reduce boredom and depression.

Local community centres offer social activities based on peoples interests and you can also choose from a range of exercise programs depending on what you like to do and how fit you are.

Decisions about using services

Most people want to stay in their own home as long as possible but you may need help with day-to-day tasks, more than what family and friends can give. There are community programs that can help you stay in your home and stay connected with your local community.

Some provide transport, or someone to accompany you on outings or activities. Speak to a family member or call My Aged Care (see page 44) to ask about these; there are many organisations like ACH Group that can help you with:

- housework
- garden and home maintenance
- getting ready for the day
- cooking meals
- transport
- social activities
- organising a holiday
- equipment and home modifications
- therapy (e.g. physiotherapy, exercise classes, podiatry)
- home nursing.

You can choose the services you want, the way they are provided and who provides them. You also have the right to say no to a service if it does not meet your needs or you are not happy with it. You can still decide to use a service at another time.

Aged Care Eligibility and Assessment

You will need an assessment if you want to:

- use certain services such as home support services or a home care package
- have short stays in an aged care facility or respite cottage
- move permanently to an aged care facility.

It may take weeks to get an appointment for an assessment so it is important to organise this early on if you need more help. Call My Aged Care (see page 44) to arrange a member of the assessment team to meet with you (and a family member/s if you want), to talk about your situation and work out the type of support that you may need.

Decisions about where you live

Where you live is an important decision; you need to think about what you need now as well as what you may need in the future. You can choose to:

- stay in your current home
- live with your family
- move closer to family or where there are community services
- ‘downsize’ to an independent living unit, close to a residential aged care facility in case you need it in the future.

Talk about where you want to live with family members ahead of time not just when you can’t be cared for in your own home anymore. Talk about the issues or events that would make you decide to move to an aged care facility.

For example:

- ‘I want my relative to care for me at home for as long as they can.’
- ‘I prefer to live in an aged care facility rather than with family if I am no longer able to look after myself.’
- ‘If I need to move into an aged care facility, I would like it to be near my daughter so she can visit.’
- ‘I am an outdoors person and would like the activities organised for me to take account of this.’
- ‘Regardless of my mental condition, I want to attend a church service each week.’

‘I made my wishes known to Mary that when the time came and she couldn’t handle me, or I became a danger to myself or others, I should move to a home. When a person gives their word it carries weight. You take away the guilt that they might have. I have made my decisions clear.’

(Peter, with dementia)

Emergency plans

While you can't prepare for all emergencies, planning ahead helps you to get the support you need if anything happens to you. Talk with your family about your concerns and plans. Things you can do include:

- organising an emergency care plan – even if you never use it. The Commonwealth Carelink and Respite Centre can help you with this
- having a personal emergency alarm system. A rebate scheme is available for eligible individuals from the SA Government
- recording emergency contact details for family and friends as I.C.E. (In Case of Emergency) 1, 2, 3 on your mobile phone or on speed dial on your home phone
- having up to date medical information on your fridge; storing your Advance Care Directive in an Emergency Medical Information booklet (available from SA Ambulance Service)
- arranging Ambulance cover
- organising a 'Safe Return' bracelet and Identification cards from Alzheimer's Australia SA if you experience memory loss and are inclined to get lost. These will assist in returning you home
- Medic alert bracelet – you can arrange this with your doctor.

● ● ● **More information? See Emergency Plans page 47-48.**

Medical care and treatment decisions

Getting information

If you have a chronic health condition, understanding the illness can help you to accept it and live more positively with the changes you are experiencing. If you need more information, you might:

- talk to your doctor or specialist
- call a community organisation (e.g. Heart Foundation, Arthritis SA).

If you are experiencing memory loss or have a diagnosis of dementia:

- ring the Dementia Helpline on 1800 100 500
- talk to a counsellor from Alzheimer's Australia SA
- find helpsheets at www.fightdementia.org.au
- attend a 'Living with Memory Loss' group run by Alzheimer's Australia SA.

● ● ● **More information? See More Information page 42.**

Care and treatment decisions

Some medical decisions you may want to think about ahead of time include:

- taking medications to treat the symptoms of illness
- being part of research trials for new drugs
- what medical and dental treatment you would or wouldn't want to receive
- what treatment and care you would like at the end of your life.

Making your wishes known

To let people know what you want:

- speak with your family, close friends and doctor
- choose someone to make medical decisions if you can't yourself and let them know what you want
- fill out an Advance Care Directive which records the medical treatment you want or do not want towards the end of your life, if you can't make or communicate decisions yourself
- give copies of your directive to your chosen decision maker(s)
- put a copy of your Advance Care Directive in your Emergency Medical Information booklet on your fridge to inform the Ambulance Service (especially Do Not Resuscitate orders) and carry one in your purse or wallet
- register your Advance Care Directive with Medic Alert if you have a bracelet
- upload a copy to your Australian Government My Health Record (myhealthrecord.gov.au).

● ● ● **More information? See Planning Ahead page 45.**

End of life medical care and treatment

Making a decision about medical care for the end of your life might be confusing, awkward and hard to talk about. Having an Advance Care Directive will help your family make difficult decisions. If you have an illness or chronic disease or develop one, you can give specific instructions about treatment, or you can:

- write down what you believe in and value
- include sentences such as 'where possible' or 'unless there are significant changes.'

These sentences can let somebody know your wishes without putting a limit on your treatment choices. Some questions to think about:

- What would you want from future medical care?
- What is more important to you - living longer or quality of life?
- Do you have any religious or spiritual beliefs which are important to you which might influence your decisions?
- Where would you prefer to receive end of life care - hospital or home?
- If your heart stops would you want to be resuscitated?
- Would you want intensive treatments to prolong your life, or would you prefer palliative care – e.g. to be kept comfortable and free from pain and let the illness take its course?
- When would you want to refuse or discontinue treatment to prolong your life?
- Do you want to be an organ donor?

● ● ● **More information? See Towards End of Life page 48.**

Financial decisions

Enduring Power of Attorney – financial decisions

An Enduring Power of Attorney lets you choose someone to make decisions about your financial and legal matters. This is different from an Advance Care Directive, which instructs someone about what to do for your medical care, personal matters and treatment at end of life.

It is advisable to make any desired changes to existing legal and financial documents and arrangements as early as possible.

Getting your affairs in order

- ☐ are your insurance, mortgage and financial papers in order?
- ☐ have you gotten advice about the management of your finances?
- ☐ written down your wishes and chosen someone to manage your financial and legal matters in an Enduring Power of Attorney?
If so, have you reviewed it recently?
- ☐ have you made a relative an authorised signatory to your bank accounts so they can continue to manage them for you if you are not able to do so, without any change in arrangements?
- ☐ have you made a relative a nominee to help with Centrelink, Department of Veterans' Affairs matters, or Government utilities?
- ☐ have you checked out your superannuation, insurance policies, benefits and entitlements, if you now need to leave work?
- ☐ have you completed a Will? If so, have you reviewed it recently?
- ☐ do you have a funeral plan or told your wishes for your funeral?
- ☐ are legal and financial documents in a secure place? Does someone you trust know where they are? Are they listed somewhere?

● ● ● **More information? See Planning Ahead page 45.**

For Families

PLANNING AHEAD

IN THIS CHAPTER

Planning for a good life	20
--------------------------	----

Planning ahead... for greater peace of mind	24
---	----

Lifestyle and medical decisions	28
---------------------------------	----

Financial decisions	32
---------------------	----

Towards End of Life... comfort and dignity	34
--	----

Planning for a Good Life... last words	38
--	----

Planning for a good life

As family members, you are often the people who know the likes and needs of your relative the best. Knowing what is important to the person helps them to live a good life.

This section of the guide talks about how to support someone to live as active a life as possible and with comfort and well-being through to the end of life. You may want to read the whole booklet to understand what is involved or read only the sections that interest you.

There are three main topic areas:

- Planning for a good life – decisions about the quality of life for you and your relative
- Planning ahead – knowing and respecting your relative's wishes and filling out Advance Directives
- Towards end of life – decisions about comfort, care and dignity at the end of life.

The **More information?** section (page 42) at the back of the booklet lists key organisations that can provide you with further information and support.

The **Planning Ahead Checklist** is also included to help with decision-making along the way – see page 50.

'People need to think about where to live. For example a move from a house to a unit, like we did. Bruce was still able to come here and adjust to moving. If we'd stayed in our old home too long, maybe he would have resisted. Here we've got lots of activities.'

(Ruby, family member)



Getting information

Supporting an older relative can be rewarding but also confusing, frustrating and overwhelming at times. Knowing more about health issues can help you to cope in a more positive way. You can:

- talk to their doctor or specialist
- contact a community organisation for support and information (e.g., Heart Foundation, Arthritis SA)
- register with Carers SA or Carer Support
- join a carers' group to meet other people who are in a similar situation. This can help with emotional support and practical ways to deal with symptoms of an illness
- contact information and support services for older persons (see **More Information**, page 42).

'I went to carers' groups and I learnt a lot about services and bits of information that are helpful. You're with people who can understand...who have experienced or are experiencing the same fears and problems.'

(Jim, family member)

If your relative has memory loss or a diagnosis of dementia, Alzheimer's Australia SA have services to support families caring for people with any type of dementia including:

- Dementia Helpline on 1800 100 500
- information sessions about dementia
- counselling services
- dementia helpsheets www.fightdementia.org.au
- Living with Memory Loss groups. These groups have a positive focus on maintaining and enhancing skills and abilities and exploring ways of managing now and in the future
- Carer Support groups.

Keeping your relative healthy and active

It is common for older people to stop activities that they used to enjoy. Some people have health conditions that change how they move, how they feel, how much energy they have or how to plan or organise themselves.

They may worry or lose confidence in what they can do. You can help with this.

Keeping your relative involved in activities and tasks around the home and in the community can:

- give them enjoyment and pleasure
- keep them in touch with friends and the local community
- help keep their skills, abilities and independence
- increase their confidence and well-being
- give them more control over their life
- reduce boredom and depression.

There are community programs to help manage life at home and to stay involved in the local community. Some services provide transport or someone to go on outings or community activities. Local community centres have a range of interest-based and social activities. Exercise programs are also available for a range of interests and fitness levels. Call My Aged Care or ACH Group for more information.

Dealing with changes

Looking after someone can change your relationship and lifestyle. It may make you feel stressed, resentful or scared about the future. These feelings are normal.

You may find it helpful to talk to someone such as your doctor or a counsellor. Some people join a carers' group where they can talk about their feelings and experiences with other people. Taking a break from caring can also help you to relax and think more clearly.

'The best you can do is to have a conversation around the table with the whole family and not just focus on one person.'

(Geoff, family member)

Looking after yourself

Taking a break

If you care for a relative it is important to have balance in your life and look after your own health. Taking a break lets you have your own interests and relationships and gives you a rest. Friends or family members can spend time with your relative or there are services that provide respite care. Respite can be used every now and then or on a regular basis, for a few hours to a few weeks.

Respite can be:

- in your own home
- in a respite cottage, day based centre or for overnight stays
- on outings or holidays
- in an aged care facility.

Respite lets your relative be with other people, be involved in different activities and helps them get used to other people caring for them.



Planning ahead... for greater peace of mind

Financial assistance for carers

Carer Allowance & Carer Payment

If you care for a person (daily) with a severe medical condition e.g. dementia, you can receive a Carer Allowance. Care can be in your home or the home of the person you care for. This is not taxed, income and assets tested and can be paid in addition to the Carer Payment or any other Centrelink payment or salary.

The Carer Payment is an income support payment for carers who can't support themselves through paid employment due to their caring role. You don't have to live with or near the person you care for, but the care must be regular. This is income and assets tested for the carer and the person being cared for. You can't receive it if you receive another type of income support payment (e.g. Aged Pension).

Understanding and respecting wishes

Growing older can make a person unsure about the future. It can be hard to talk about finances, care and medical treatment. It is important to make plans and talk about the future early while the person is still able to talk about what they want. Planning ahead can help you to:

- think about things calmly, when there's no crisis to deal with
- speak with the person about things that are important to them
- have more time to ask questions and look for professional help (e.g. from a doctor, solicitor)
- think about past decisions and change them if needed.

You can speak with your relative about:

- where they want to live and who with
- recreational activities and holidays they would enjoy

- who they would like to have contact with
- how they would like their financial matters looked after
- their choice of doctor, other health professionals and dentist
- their thoughts about quality of life and their care and treatment at the end of life.

It helps to write down what you talk about, in notes that can be looked at again at a later time, or in an Advance Care Directive if your relative can still make decisions for themselves.

‘Tom doesn’t want to talk about it but when a story comes up on TV, or sometimes if we’re talking about another person’s situation, I’ll say “Well, what would you like?”’

(Glenys, family member)

Decision-making capacity

Your relative will need to be able to show that they understand what any documents are about and the end result of the decisions they are making before they complete an Advance Directive. This is called decision-making capacity. This can be affected by ill health, medications and some health conditions such as dementia, brain injury and stroke.

A person with a lot of health problems or with early dementia may still be legally able to make financial, personal and lifestyle decisions and to let people know about their wishes. If you’re not sure of your relative’s decision-making capacity, this can be checked by a doctor or specialist. For dementia, as the condition progresses, the ability to make decisions will decrease and it is therefore best to organise an Advance Directives early after diagnosis.

Advance Care Directives

An Advance Care Directive is a formal way for your relative to:

- Write down their wishes, preferences and instructions for future health care, living arrangements, personal matters and end of life
- Chose one or more people (Substitute Decision-Maker) to make decisions for them if they are unable to in the future.

An Advance Care Directive is put in place at any time when a person’s decision making capacity is affected. This may be temporary or permanent.

It's a good idea to regularly check the Advance Care Directive to see if it's still appropriate or to write sentences such as 'where possible' or 'unless there are significant changes.' This lets somebody know about a person's wishes without limiting their treatment choices.

An Enduring Power of Attorney is different from an Advance Care Directive and allows a person to choose someone to make financial decisions for them. It starts from the time a person is no longer able to make decisions for themselves.

It is a good idea for every adult to make these Advance Directives

Who can help with Advance Care Directives?

Legal issues can be confusing. You can get information and advice from the Office of the Public Advocate and the Legal Services Commission (see Planning Ahead, page 45-46).

You can also talk to:

- your family members and close friends
- your doctor
- a community care or aged care provider
- your financial advisor
- your solicitor.

You can choose to prepare the Advance Care Directives:

- with a Do it Yourself Kit or online
- with the help of a solicitor or a trustee company
- with the help of your relative's doctor.

● ● ● **More information? See Planning Ahead page 45-46.**

When your relative is unable to make their own decisions...

Speaking 'on behalf' of your relative

If you are making decisions for your relative, you must make decisions that take into account:

- the decision the person would make if they could
- the wishes of the person before they lost the ability to make their own decisions

- the person's values and beliefs
- professional advice.

This is called 'substitute decision making.'

Acting in their 'best interests'

If you do not know what your relative would want to do in a certain situation or it's not possible to follow their wishes, you need to act in their 'best interests.' You need to be aware of any 'conflicts of interest' between your needs and their wishes. Think about past conversations and what has been important to your relative in their life. Talk to other family members about important decisions.

Informal arrangements

If the person has not made an Advance Directive and no longer has decision-making capacity, informal arrangements are usually respected by law. You may already be:

- a nominee for Centrelink
- a signatory on bank accounts
- organising services for them
- agreeing (giving consent) to medical and dental treatment.

In financial matters, privacy issues, bank rules and legal issues can prevent what can be done after the person loses capacity. Most arrangements can continue unless:

- there is a disagreement about the decisions being made
- their financial affairs are complex
- there is a need to sell property.

When this happens someone may need to be legally chosen by the South Australian Civil and Administrative Tribunal (SACAT) to look after the person's affairs.

The South Australian Civil and Administrative Tribunal (SACAT)

The SACAT is a government tribunal that decides about the lives and property of people who are no longer able to make decisions for themselves. If there is no Advance Directive in place, you can apply to the SACAT to be 'legally appointed' to look after your relative's affairs. The Office of the Public Advocate has information sheets and can give advice on these matters.

Lifestyle and medical decisions

Advance Care Directive – Lifestyle and medical decisions

You may need to make decisions for your relative about what services they need, where they live, their leisure activities and holidays and what medical treatment they do or do not want.

Lifestyle decisions

Decisions about using services

If you care for your relative at home it's important to ask for help and plan for what you might need in the future. Family and friends can help and community services are available to provide quality of life for you both. A range of organisations like ACH Group can help with:

- housework
- garden and home maintenance
- getting your relative ready for the day
- meal preparation
- transport
- social activities for your relative
- respite programs to give you a break from your caring responsibilities
- organising a holiday
- equipment and home modifications
- therapy (e.g. physiotherapy, exercise classes, podiatry)
- home nursing.

You and your relative can choose the services you want, decide how they are provided and who provides them. You can refuse a service if it does not meet your needs and still use a service at a later time. ACH Group or My Aged Care can help you with this.

Decisions about care

At some point you may need to decide if you can still care for your relative at home.

Questions to think about include:

- What is their general health like?
- Do they have an illness to manage?
- Are you able to keep them safe at home?
- Can I give the emotional support and physical care they need?
- Am I able to provide activities for them?

'I made my wishes known to Mary that when the time came and she couldn't handle me, or I became a danger to myself or others, I should move to a home. When a person gives their word it carries weight. You take away the guilt that they might have.

I have made my decisions clear.'

(Peter, with dementia)

Think about your own needs:

- How is your health?
- How are your energy and stress levels?
- Are you able to take time out to care for yourself?
- Do you have adequate support from family and friends?
- Is appropriate help available to you from community services?
- Do you have other demands on your time (e.g. family, work)?



'I had really stretched the elastic. At the time David went into care, I was a sick person. At the time you just don't see it.'

(Jan, family member)

Speak to people who understand your situation or maybe a counsellor. Respite in a community respite house or aged care facility can be a 'stepping stone' to permanent care if needed. The change to residential care can be hard, it takes time to adjust.

Medical care and treatment decisions

Talk about medical decisions with your relative while they are still able to let you know what they want. Talk about:

- taking medications for the symptoms of their health conditions
- being part of research trials for new drugs
- the medical and dental treatment they do or don't want
- the care and treatment they want at the end of their life.

Talk to your relative's doctor ahead of time about how to care for your relative at home if they are ill, or about why they might end up in hospital. If your relative is in a care facility, talk to staff about what care can be given.

Going to hospital

Being in hospital can be confusing for older people as they are away from their familiar environment and day to day activities. Some medical procedures (e.g. blood tests, x-rays, scans, intravenous therapy, feeding tubes) or surgery can be frightening and distressing and may not greatly improve their quality of life.

If your relative goes to hospital, you need to be able to let staff know about the care your relative wants in certain situations. Medical decisions can be very confusing and you need to think hard about quality of life issues for your relative and what they want. Have copies of their Advance Care Directive to show to staff.

‘I was totally unprepared so it was a terrible shock when I needed to make those decisions. It would have been helpful if I’d actually thought about it, or talked about it or done something about it before I was actually sitting at the hospital being asked these questions.’

(Gina, family member)

Emergency plans

Planning ahead can give you peace of mind so that if anything happens to you, the person you care for will still receive support. Talk to your relative and other family members about your concerns and plans.

While you can’t be totally prepared for emergencies, you might think about:

- organising an emergency care plan – even if they never use it. The Commonwealth Carelink and Respite Centre can help you with this
- having a personal emergency alarm system. A rebate scheme is available for eligible individuals from the Department for Communities and Social Inclusion
- recording emergency contact details for family and friends as I.C.E. (In Case of Emergency) 1, 2, 3 on your relative's mobile phone or on speed dial on their home phone
- having up to date medical information on their fridge; storing the Advance Care Directive in an Emergency Medical Information booklet (available from SA Ambulance Service)
- arranging Ambulance cover
- organising a ‘Safe Return’ bracelet and Identification cards from Alzheimer’s Australia SA if your relative has memory loss and are inclined to get lost. This will help them to return home
- Medic Alert bracelet – you can arrange this with your doctor.

● ● ● **More information? See Emergency Plans page 47-48.**

‘Who will take over the caring if something happens to me?’

(Doug, family member)

Financial decisions

Advance Directives – Financial decisions

An Enduring Power of Attorney allows you to record your wishes and appoint someone to 'speak for' you in the management of your financial and legal affairs from when you lose decision-making capacity.

A Will allows you to give instructions about how you would like your assets to be distributed after you die and enables you to appoint an executor to carry out your wishes.

Getting affairs in order

It's a good idea for your relative to make any changes to current legal and financial documents and arrangements as early as possible.

Has your relative:

- ☐ got their insurance, mortgage and financial papers in order?
- ☐ received advice about the management of their finances?
- ☐ written down their wishes and chosen someone to manage their financial and legal matters in an Enduring Power of Attorney?
If so, have they reviewed it recently?
- ☐ made someone an authorised signatory to their bank accounts so that they can be managed if they are not able to do so, without any change in arrangements?
- ☐ made someone a nominee to help them with Centrelink or Department of Veterans' Affairs, or Government utilities?
- ☐ checked their superannuation, insurance policies, benefits and entitlements, if they now need to leave work?
- ☐ completed a Will? If so, have they checked it recently?
- ☐ made a funeral plan or talked about their wishes for a funeral?
- ☐ made sure legal and financial documents are kept in a safe place?
Does someone they trust know where they are kept? Is that person listed somewhere?

'Mentally I'm free now of all that's expected of me for the future.

It was a case of his beliefs and his particular expectations.

It doesn't make it an end of life decision. It's like an ordinary conversation. "What would you like?" "Have you thought about...?"

It's taken away the pressure of it.'

(Diane, Family member)

Enduring Power of Attorney

If your relative has appointed you as their Enduring Attorney you have a responsibility to:

- exercise the power honestly and with reasonable care to protect their interests
- not enter into transactions that may involve a conflict of interests between you and your relative
- keep their money and property totally separate from your money and property
- keep proper accounts and records of how you manage their money and property.



Towards end of life... comfort and dignity

End of life treatment and care

End of life care is care in the last weeks, days or hours of a person's life. Medical treatment and care decisions at the end of life are difficult and can be hard to talk about.

Some questions to think about with your relative ahead of time are; do they:

- want end of life care in hospital, a care facility or at home?
- want intensive treatments to extend their life or palliative care e.g. kept comfortable, pain free and the illness takes its course?
- want to refuse or stop treatment which would extend their life?
- want to be resuscitated if their heart stopped?
- want to donate their organs?

While your relative can still make decisions they may:

- write down the medical care and treatment they do or don't want at the end of life and give to the person making decisions. This can be written in notes or an Advance Care Directive.
- put a copy of their Advance Care Directive in the Emergency Medical Information booklet and put on the fridge for the Ambulance Service
- register their Advance Care Directive with Medic Alert
- upload a copy of their Advance Care Directive to their Australian Government My Health Record
- make changes to their Advance Care Directive
- register as an organ donor.

If your relative has not written down their wishes or can't make decisions for themselves, you can:

- think about what has been important to them
- try to remember past conversations about what they wanted
- talk with family members, close friends or your relative's doctor
- ask your relative's doctor to write down important decisions (like Do Not Resuscitate orders) in a letter to put in the Emergency Medical Information booklet for the Ambulance Service.

Keeping your relative at home

Caring for someone at the end of life can be rewarding but also difficult physically and emotionally. To decide whether you can provide care think about what your relative wants, the medical needs of your relative and your mental, emotional and physical health. You need to know where to get help when you need it. My Aged Care can link you with ACH Group who can:

- organise for a careworker (who may be familiar) to visit
- let you know about extra help from a Registered Nurse
- organise for equipment and/or changes in your home to make your relative more comfortable
- talk to your relative's doctor or Specialist Palliative Care service when you need to.

Looking after yourself

You can feel lots of emotions as your relative's health condition changes and you anticipate their death.

If you care for them at home:

- get support from family, friends and services
- try to eat a healthy diet, get exercise and adequate sleep and take time out from caring
- talk to the doctor or anyone in the care team when you have questions or worries about your health or the care of your relative
- know your limits.

The care team

The team of people who can help you to give the best care for your relative at the end of life might include:

- family members and close friends
- minister of religion or spiritual advisor
- doctor/s
- Pharmacist
- nurse
- visitors
- service advisor or care workers from an organisation such as ACH Group
- Specialist Palliative Care service; specialist doctors, nurses, and social workers to give you advice on care and services.

You can meet with the care team to talk about:

- your relative's wishes (notes or Advance Care Directive)
- how to give comfort and relief
- what to do in emergencies
- the purpose, type and limits of any ongoing treatment
- who will give the care.

Being prepared

You may need to make difficult and complex medical decisions at a very emotional time. Ask questions and get professional advice about the right care and treatment. Medical staff may suggest invasive procedures (e.g. surgery, life support, intravenous antibiotics, artificial nutrition and hydration, blood transfusions, x-rays and scans). These procedures might cause distress and discomfort without making much difference to quality of life.

You may need to decide whether to keep your relative at home, in their care facility or have them transferred to hospital. Discuss this with other family members; get advice from your relative's doctor or others in the care team or at their care facility. Think about your relative's beliefs and values about quality of life.

If an Advance Care Directive is in place, these instructions will guide your decisions; follow them as closely as possible. Some decisions may need to be re-thought due to new medical treatments, changes in health condition or what support services are available.

If you do not know what your relative would want, or you can't follow their wishes, you need to act in their 'best interests.' This means thinking about their needs and making a decision that is the best one for them.

Think about:

- How helpful is the treatment for your relative?
- What choice gives the most comfort to your relative?

The goal is to plan for a respectful, comfortable and pain free death surrounded by people who can give comfort and care.

● ● ● **More information? See Towards End of Life page 48.**

Planning for a good life... last words

This guide is to help you encourage your relative to talk about and write down their wishes about important decisions while they are still able to, so that they can stay in control.

This will help you to honour their wishes and support them to have a good life as they grow older.



USEFUL CONTACTS

IN THIS CHAPTER

Useful contacts list	40
----------------------	----

More information?	42
-------------------	----

Planning ahead checklist	50
--------------------------	----

Useful contacts

Contact	Name	Telephone	Email
Doctor			
Pharmacist			
Advisor			
Counsellor			
Friends/ neighbours			
Community nurse			
Minister of religion or spiritual advisor			

Contact	Name	Telephone	Email
Enduring Attorney(s)			
Substitute Decision Maker(s)			
Other			

NOTES

More information?

INFORMATION AND SUPPORT

ACH Group

to be linked with the ACH Group services in your area.

Tel: 1300 22 44 77

www.ach.org.au

Alzheimer's Australia SA

for information, living with memory loss groups, education programs, counselling, carers' groups, helpsheets for people with dementia and family carers.

Dementia Helpline

Tel: 1800 100 500

www.fightdementia.org.au

Arthritis SA

for support, information, education sessions and support groups relating to arthritis and related conditions.

Tel: 8379 5711

www.arthritissa.org.au

Carers SA

for information, advocacy, counselling, carers' groups and programs and a free Carer Support Pack with information sheets on a range of caring issues.

Tel: 1800 242 636

www.carers-sa.asn.au

COTA SA

for information, advocacy, services and community programs for older people.

Tel: 8232 0422 or 1800 182 324

(country callers)

www.cotasa.org.au

Dementia Behaviour Management Advisory Service

for 24 hour telephone advice and support and referral to other health professionals.

Tel: 1800 699 799

www.dbmas.org.au

Heart Foundation

for information and advice on heart health, healthy eating and active living.

Tel: 1300 362 787

www.heartfoundation.org.au

Translating and Interpreting Service

for 24 hour a day, seven days a week telephone interpreting service.

Tel: 131 450

Medicines Line

for information about medicines including prescription medicines, over the counter medicines, complementary medicines and herbal and natural therapies.

Tel: 1300 633 424

www.medicinesline.com.au

FINANCIAL ASSISTANCE

Centrelink

for information about Carer Payment and Carer Allowance.

Tel: 132 717

www.humanservices.gov.au

USING SERVICES

ACH Group

to be linked with the ACH Group services in your area.

Tel: 1300 22 44 77

www.ach.org.au

Commonwealth Carelink and Respite Centre

Tel: 1800 052 222

Department of Veterans' Affairs

for information about services to support Australian veterans.

Tel: 13 32 54

www.dva.gov.au

Independent Living Centre

for information about equipment and aids to assist people to live independently.

Tel: 1300 885 886

www.ilcaustralia.org.au

My Aged Care

for information about services to assist people to stay at home.

Tel: 1800 200 422

www.myagedcare.gov.au

Seniors Information Service

for information about the transition to an aged care facility and current vacancies in aged care facilities.

Tel: 8168 8776 or 1800 636 368 (country callers)

www.seniors.asn.au

PLANNING AHEAD

Alzheimer's Australia

Start to Talk website - a comprehensive resource on planning ahead for people across Australia (information is available in 30 languages).

www.start2talk.org.au

Australian Organ Donor Register

for information about organ donation and registration as an organ donor.

Tel: 1800 777 203

www.humanservices.gov.au

Australia Post

for Prepare Your Own Packs for Enduring Power of Attorney and Wills.

Law Society of South Australia

for a list of solicitors who may assist with the preparation of Advance Directives.

Tel: 8229 0200

www.lawsocietysa.asn.au

Legal Services Commission SA (city and regional offices)

for advice and forms for Enduring Power of Attorney and Advance Care Directives.

Tel: 1300 366 424

www.lsc.gov.au

Medic Alert Foundation

for registration of an Advance Care Directive.

Tel: 8273 8401 or 1800 882 222

Office of the Public Advocate

for advice and fact sheets about Advance Care Directives, SACAT and legal issues.

Tel: 8342 8200 or 1800 066 969 (country SA only)

www.opa.sa.gov.au

Palliative Care Australia

for information on services and a discussion starter.

www.dyingtotalk.org.au

Public Trustee

for assistance in witnessing Advance Care Directives and preparing Enduring Power of Attorney.

Tel: 8226 9200 or 1800 673 119 (country SA only)

www.publictrustee.sa.gov.au

Service SA (city and regional offices)

for Do it Yourself Kits for Enduring Power of Attorney Advance Care Directives.

Tel: 13 23 24

www.service.sa.gov.au

SA Health

for Advance Care Directive Kit and Form

www.advancecaredirectives.sa.gov.au

The South Australian Civil and Administrative Tribunal (SACAT)

for issues and dispute resolution.

Tel: 1800 723 767

www.sacat.sa.gov.au

EMERGENCY PLANS

Carers VIC

for information on making an emergency care plan.

www.carersvictoria.org.au/advice/plan-ahead/emergency-plans



Health Direct 24 Hour helpline

for 24 hour health advice from registered nurses on which health service can help, level of urgency and what to do until you receive face to face medical attention. Try your doctor first.

Tel: 1800 022 222

www.healthdirect.gov.au

Independent Living Centre

Tel: 1300 885 886

www.ilcaustralia.org.au

SA Ambulance Service

for Ambulance cover, Emergency Medical Information Booklet and Call Direct personal alarm.

Tel: 1300 136 272

www.saambulance.com.au

TOWARDS END OF LIFE

Caresearch

for information on palliative care decisions and specialist palliative care services.

www.caresearch.com.au

Grieflink

for information on grief.

www.grieflink.asn.au

Lifeline

for 24 hour counselling service.

Tel: 13 1114

www.lifeline.org.au

Palliative Care South Australia Inc

for information and advice on palliative care decisions, specialist palliative care services and preparing Advance Care Directives.

Tel: 8271 1643

www.pallcare.asn.au

AT TIME OF DEATH

Centrelink

for information about financial and legal matters at time of death and Bereavement Payments, Bereavement Allowance and Widow Allowance.

Tel: 13 23 00

www.humanservices.gov.au

Department of Veterans' Affairs

for bereavement support and financial assistance including a funeral benefit to Australian veterans who are Gold Card holders or war widows.

Tel: 13 32 54

www.dva.gov.au

Planning ahead checklist

Have you...	Page	<input checked="" type="checkbox"/>
Information and Support		
Contacted the relevant community organisation about your health condition or that of your relative (e.g. Arthritis SA, Alzheimer's Australia SA, Heart Foundation)?	42-43	
Contacted COTA Seniors Voice, local aged care organisations or your local council to find out about services and community programs to stay healthy and active?	43-44	
Contacted Carers SA for information and a Carer Support Pack if you are caring for an older relative?	42, 47	
Planning ahead		
Talked with your relative and doctor about future care and treatment preferences?	10, 25	
Completed Advance Directives (Will, Enduring Power of Attorney, and Advance Care Directive)	9, 12, 25, 28, 32, 34, 36	
Reviewed them recently?	18	
Know where they are kept?	9, 18, 32, 34	
Reviewed banking and bill-paying arrangements?	18	

Have you...	Page	
Updated financial and legal documents and filed them in a safe place?	18, 32	
Contacted Centrelink about Carer Allowance and/or Carer Payment?	24	
Using services		
Organised an Aged Care Assessment?	13	
Asked your service advisor about services available in your local area?	12, 22	
Planned some time out for yourself if you are caring for an older relative?	29, 35	
Emergency plans		
Organised a plan for the care of your relative in an emergency?	15, 31, 47	
Displayed an up to date Emergency Medical Information booklet (from SA Ambulance) on your fridge including a copy of your Advance Care Directive or letter from your doctor about end of life wishes?	15, 31, 34	
Recorded emergency contact details as I.C.E.1, 2, 3 ... (In Case of Emergency) on your mobile phone or on speed dial on your home phone?	15, 31	
Subscribed to Ambulance Cover?	15, 31	
Organised a 'Safe Return' bracelet and identification cards from Alzheimer's Australia SA (if your relative has dementia and is inclined to get lost)?	15, 31	

ACH Group

22 Henley Beach Road
Mile End SA 5031

Tel: 1300 22 44 77

Fax: (08) 8159 3777

ach@ach.org.au

www.ach.org.au

Aged Care & Housing Group Inc.
ABN 99 437 071 895

