



GUIDE

Allied health professionals and you: a guide for people living with dementia and their carers



The Agency for Clinical Innovation (ACI) works with clinicians, consumers and managers to design and promote better healthcare for NSW. It does this by:

- *service redesign and evaluation* – applying redesign methodology to assist healthcare providers and consumers to review and improve the quality, effectiveness and efficiency of services
- *specialist advice on healthcare innovation* – advising on the development, evaluation and adoption of healthcare innovations from optimal use through to disinvestment
- *initiatives including guidelines and models of care* – developing a range of evidence-based healthcare improvement initiatives to benefit the NSW health system
- *implementation support* – working with ACI Networks, consumers and healthcare providers to assist delivery of healthcare innovations into practice across metropolitan and rural NSW
- *knowledge sharing* – partnering with healthcare providers to support collaboration, learning capability and knowledge sharing on healthcare innovation and improvement
- *continuous capability building* – working with healthcare providers to build capability in redesign, project management and change management through the Centre for Healthcare Redesign.

ACI Clinical Networks, Taskforces and Institutes provide a unique forum for people to collaborate across clinical specialties and regional and service boundaries to develop successful healthcare innovations.

A priority for the ACI is identifying unwarranted variation in clinical practice and working in partnership with healthcare providers to develop mechanisms to improve clinical practice and patient care.

www.aci.health.nsw.gov.au

AGENCY FOR CLINICAL INNOVATION

Level 4, Sage Building
67 Albert Avenue
Chatswood NSW 2067

PO Box 699, Chatswood NSW 2057

T +61 2 9464 4666 | F +61 2 9464 4728

E info@aci.nsw.gov.au | www.aci.health.nsw.gov.au

(ACI) 160272, ISBN 978-1-76000-460-6

Produced by: Aged Health Network

Further copies of this publication can be obtained from the Agency for Clinical Innovation website at www.aci.health.nsw.gov.au

Disclaimer: Content within this publication was accurate at the time of publication. This work is copyright. It may be reproduced in whole or in part for study or training purposes subject to the inclusion of an acknowledgment of the source. It may not be reproduced for commercial usage or sale. Reproduction for purposes other than those indicated above requires written permission from the Agency for Clinical Innovation.

Version: V1

Date amended: June 2016

© Agency for Clinical Innovation 2016

This booklet talks about how you can improve your life by talking to allied health professionals.

Allied health professionals include:

- Aboriginal and Torres Strait Islander health workers (these workers will have different titles in different states and territories)
- audiologists
- Chinese medicine practitioners
- chiropractors
- counsellors
- dementia advisors and key workers (see note below)
- dental therapists, dental hygienists and oral health therapists
- dietitians
- diversional therapists
- exercise physiologists
- music therapists
- occupational therapists
- optometrists
- osteopaths
- pharmacists
- physiotherapists
- podiatrists
- psychologists
- neuropsychologists
- social workers
- speech pathologists.

Note: Dementia advisors (sometimes known as key workers) are available in some states and territories. Most are allied health professionals (or nurses) with considerable experience or further training in working with people with dementia. They are included in this publication although they are not available throughout Australia.

What dementia is and what it isn't

Dementia describes a collection of symptoms that are caused by disorders affecting the brain. It is a neurodegenerative process that affects cognition (thinking), communication, behaviour and the ability to do everyday things. Dementia is not one specific disease. Alzheimer's disease is the most common form of dementia. There are many other types of dementia that can impact on a person in different ways. Each person's experience of dementia will be different.

In all types of dementia, brain function is affected enough to interfere with the person's normal life. Dementia is not a normal part of ageing. It is not a mental illness. Dementia can happen to anybody, but it is more common after the age of 65 years. At present there is no cure for dementia. But there are many types of support that health professionals can offer to enable people with dementia to continue to live well and enjoy life.

UNDERSTAND ALZHEIMER'S EDUCATE AUSTRALIA

Alzheimer's Australia is the peak body representing people with dementia, their families and carers. It provides advocacy, support services, education and information. More than 353,800 people have dementia in Australia. This number is projected to reach more than half a million by 2030.

FIGHTDEMENTIA.ORG.AU

For information and advice, contact the National Dementia Helpline on:

1800 100 500

The National Dementia Helpline is an Australian Government-funded initiative.

The National Dementia Helpline is a telephone information and support service available across Australia. The Helpline is for people with dementia, their carers, families and friends, as well as people concerned about memory loss, providing:

- understanding and support for people with dementia, their family and carers
- practical information and advice
- up-to-date written material about dementia
- information about other services
- details of the full range of services provided by Alzheimer's Australia.

Foreword

As a person with younger onset dementia, and a physiotherapist, I was very pleased to be asked to contribute a foreword to this very helpful document, which is aimed at encouraging the use of allied health professionals by people with dementia. When I was diagnosed with posterior cortical atrophy in my early fifties, just over four years ago, I was completely unaware that this disease was possible at that age. But in the intervening years, I have found ways to continue to live life in a meaningful and engaged way.

Since my diagnosis, I have found it very important to seek out appropriate support and put it in place earlier, rather than later. I have seen first-hand what a difference it can make to keep active and be physically, cognitively and socially engaged, as it maximises my quality of life. I have found the assistance of allied health professionals to be invaluable, and of particular help in managing the more unfortunate symptoms of dementia.

Also, since my diagnosis, I have volunteered my physiotherapy skills to run a gentle exercise group for older people with dementia in my local area. Pleasingly, this has not only benefited the people concerned, but has also given me satisfaction from helping others to maintain their health. Unfortunately, I have discovered that the use of allied health professionals is not as widespread as it could be within the dementia community, and as such, many people are not making use of the skills that this sector offers. Consequently, I feel that the production of this guide is very timely and will be of great benefit to all people in the broader community.

As a consumer of dementia-related community services, I would like to encourage the broader awareness of allied health services, and their potential benefit to consumers in maintaining their quality of life for as long as possible. I am sure that consumers would like to be able to be given assistance, wherever practical, to be involved and engaged in retaining our valued roles and activities in daily life.

I encourage people with dementia, and those who love and care for them, to read and make use of the information in this document.

Maxine Thompson

Introduction

When you have dementia, much of your life continues as it was.

You're still the same person, with the same likes and dislikes, the same culture and beliefs, the same family and community. None of that has changed.

But some other things have changed. You've been told you have a condition that will have an impact on your life. Your thinking might not be as clear as it once was. And you might not be able to get around as well as you could.

Other changes lie ahead. It helps to think about how you might adapt to change.

In recent years, health professionals have learnt a lot about ways to improve the lives of people with dementia. They understand that they should treat you with dignity at all times.

Allied health professionals – social workers, occupational therapists, dietitians, speech pathologists, physiotherapists, neuropsychologists and others – can all work with you and your carers¹ and family on this.² Some will have particular expertise in working with people living with dementia. Unfortunately, they are not all available in all parts of Australia.

If you have dementia, this booklet is for you. It doesn't matter whether you've just found out about it, or whether you've been living with dementia for years. Or what type of dementia you have. It will help you think about where you are now, where you would like to be and how you might get there.

Your GP or your geriatrician, if you have one, might be able to point you to a local allied health professional. Allied health professionals can work with you and your GP as a team to support you.

There's a lot you can do. There's a lot that others can do by working with you. Talking to allied health professionals is a good starting point. There's some overlap between what they do, so you don't need to talk to all of them. You can start with just one.

There is a companion booklet for health professionals called ***Better health for people living with dementia: A guide on the role of allied health professionals***. It has more details about the ways in which allied health professionals can help. It is available at <https://fightdementia.org.au/about-dementia/health-professionals/allied-health-professionals> or at http://www.aci.health.nsw.gov.au/_data/assets/pdf_file/0004/310837/Better-health-for-people-living-with-dementia.pdf

¹ 'Carers' is the term used in this booklet to refer to people providing care to a person with dementia. Some people prefer the term 'care partners', and some people don't like either term. It does not include paid workers who provide care. It does include carers in receipt of the Australian Government carer payment and carer allowance.

² Of course nurses, doctors, multicultural health workers and many others can help too, but this booklet concentrates on allied health professionals.

Contents

Being yourself	8
Adjusting to change	10
Information	11
Emotional and psychological support	12
Your health and wellbeing	13
Staying strong, keeping physically active	14
Staying alert, staying connected	15
Communicating	17
Eating well	18
Speaking up	20
Your voice, your future	21
Finding your way around the system	22
At home with dementia	23
Your home	24
Help in the home	25
Moving house	25
Medication management	26
Getting around	26
Changes to how you think and feel	27
Intimacy and sexuality	29
Carers, families and friends	30
Carer support groups	31
Time out	32
Later stages of dementia	33
Transition to residential care	34
End of life	35
What allied health professionals do	37
Finding an allied health professional	40
National contacts	41
Professional associations	42
Local contacts	42
Resources	43
Acknowledgements	48
About this booklet	48



Being yourself

Being yourself

You are a son or a daughter, perhaps a mother or a father, perhaps a husband, wife or partner, and perhaps a friend.

You've been to school. You've worked. You might be religious or be spiritual. You live in a certain culture, and speak the language you know best.

All those things have meaning to you. They're part of who you are, and they're still there. It's important for you, at this time, to build on the things that have meaning for you.

You have to adapt to any changes, but you will also be happiest if you can be yourself.

Occupational therapists, diversional therapists and social workers can all help you in different ways. They'll need to get to know you first – your past, your culture, your likes and dislikes – so that any suggestions they offer are right for you.

An occupational therapist can help you find activities that interest you or help you figure out ways to keep doing the things you love, in spite of the difficulties you might face. This might mean setting things up a bit differently at home, or showing you new ways to do things, like taking shortcuts.

A diversional therapist can work with you to find activities, leisure and outings that interest you. They will work with you to make sure they are enjoyable, not stressful.

A social worker can help you find the right allied health professional or service. So can an Aboriginal and Torres Strait Islander health worker.

Talk to

Occupational therapist

Diversional therapist

Social worker

Aboriginal and Torres Strait Islander health worker

Shaun's story

Shaun had always worked hard. When he developed dementia and had to retire earlier than he had planned to, he needed to make some big adjustments.

But adjust he has. He started working a vegetable patch at home, and now volunteers at two community gardens, earning a TAFE certificate along the way. He meets with a men's group regularly. He volunteers at church. He reads. And once a fortnight, he meets at a coffee club organised by a dementia advisor.

Between 10 and 25 people, some with dementia, some carers, meet at the same café once a fortnight to talk and relax. An allied health professional is always present to provide support and information. Shaun has found them so good he's started going to others in neighbouring areas.

“ I enjoy them. I like to feel I can support and encourage people. This is a good way of helping others out. ”



Adjusting to change

Living with dementia means living with change.

Some people move easily from one change to another and some find it more difficult. And some changes are easier to adjust to than others.

Allied health professionals can work with you to make it easier to adjust to the changes in your life.

And they can help you through some of the difficult periods that everybody faces at one time or another.

Information

You and your family might want information about dementia, about how it might affect your lives, about what the future might hold or about how to get help and support.

Alzheimer's Australia provides information, support, counselling, training and education to people with dementia, their family, friends and carers. For information on dementia and to arrange counselling, you can call the National Dementia Helpline.

Dementia advisors, occupational therapists, social workers, psychologists and neuropsychologists are good people to talk to early on. They can help you, and those closest to you, make sense of a diagnosis of dementia, and help you understand what it might mean, and what it won't mean, for your life and the lives of those who care about you. They can help guide you through this change.

If you work, they can help you think about how to continue, or other options.

They can offer information directly, and put you in touch with education sessions locally or online. They can make referrals to other health professionals who specialise in working with people living with dementia. And they can point you in helpful directions with your own research.

All allied health professionals who work with people living with dementia can be a good source of information. Speech pathologists, psychologists, neuropsychologists and dietitians may have answers to specific questions that you have.

Talk to

National Dementia Helpline
1800 100 500

Dementia advisor (NSW and Qld)

Occupational therapist

Social worker

Neuropsychologist

Psychologist

Speech pathologist

Dietitian

Emotional and psychological support

Counsellors, psychologists, neuropsychologists and social workers can provide support to you, your carers, family and friends in a non-judgemental way.

This allows people to discuss their feelings and any sense of loss, and find ways to adjust to the changes. Even if you may think counselling is not for you at this point, there may be some stage where it could be a good idea, for you or for others around you. The National Dementia Helpline (1800 100 500) is a good place to start talking with a counsellor.

Talk to

Counsellor

Psychologist

Neuropsychologist

Social worker



Your health and wellbeing

Life goes on. Whether you've had dementia for a long time or just found out about it, you will want to keep living your life as well as you can.

Staying strong, keeping physically active

There is an old saying – use it or lose it. It is true. Whether you are young or old, the more active you are, both physically and mentally, the better you will feel.

Being active has many, many benefits. It helps you feel better and sleep better. It can be social and fun and make doing daily tasks easier. And it can help you think more clearly.

It is also good for your health. It helps your heart, and helps make you stronger, steadier and more mobile.

If you would like to be more active, you can talk to a physiotherapist or an exercise physiologist. They can work with you to improve your strength, balance, mobility and endurance.

If you have problems with your muscles or joints, a physiotherapist may be able to suggest ways to reduce pain and stiffness. If you are having trouble with moving around or with your walking, they can give you exercises to help.

They can also suggest a walking aid, such as a walking stick if that might help you get around safely, and teach you how to use it.

Physiotherapists and occupational therapists can help you find the types of exercise and physical activities that you enjoy.

You might find that problems with your feet or shoes stop you getting out. If so, a podiatrist can check your feet and talk to you about comfortable and safe footwear.

Talk to

Physiotherapist

Exercise physiologist

Occupational therapist

Podiatrist

Ken's story

Within a few months of being diagnosed with dementia, Ken was having trouble walking and was using a walker.

A physiotherapist made six visits to Ken at home. She introduced a program that aimed to make him more mobile. Ken's son John did the exercise program with him.

Ken joined a day rehab program, which added different exercises. John added those to the daily at-home routine.

Within six months, Ken could walk more than 2 kilometres unassisted and got around the house more easily, though still using a stick or a walker.

The exercise has dropped off a little, although he is still walking a kilometre a day. He is also doing a regular program of exercise and hydrotherapy twice weekly. Ken is happier than before, enjoying getting out of the house and moving more freely. Some of his boredom has eased. John believes the initial visits from the physio made an enormous difference.

Staying alert, staying connected

Many people with dementia want to know if there are ways of preventing, slowing down or reversing the changes in the brain.

The research done in recent years has led to an explosion in knowledge about how the brain works.

Although nothing has yet been found to prevent or reverse dementia, research has shown that keeping the brain active, engaged and stimulated is good for your brain.

Researchers know that people with dementia may be able to learn new things and can be involved in rehabilitation (rehab) programs that keep the brain active and engaged.³

They also found that it's good for your mind to learn something new, if possible. You could enrol in a course, sing with a choir, join a dance class. Or join a program designed for people with dementia to keep your brain active and stimulated.

There are many other ways to keep your mind active; they also keep you connected to the world.

Noelene's story

Noelene loves music, loves to sing and loves to dance. She always has. Her house was full of music and she used to sing her children to sleep every night. Noelene's love of music and singing has not changed even though some other things have. When Noelene's skills in using her CD player changed, her son and daughter put all her music onto an iPod and with the press of just one button, Noelene can continue to enjoy all the music she loves.

These might be:

- seeing family and friends, or making new friends
- staying involved with your community, club, religious group or sporting group
- joining groups for activities, outings and fun
- reading, doing puzzles and playing games.

If you'd like some support with this, occupational therapists, psychologists, neuropsychologists and diversional therapists are the professionals to talk to. They can find out about your interests and abilities; and maybe point you towards rehab. You'll enjoy it more if it's something that interests you. And music therapists can provide specialised help.

Talk to

Occupational therapist

Psychologist

Neuropsychologist

Diversional therapist

Music therapist

³ Clinical practice guidelines and principles of care for people with dementia; 2016 Sydney. National Health and Medical Research Council Partnership Centre for Dealing with Cognitive and Related Functional Decline in Older People. <http://sydney.edu.au/medicine/cdpc/documents/resources/dementia-guidelines-full-document-website.pdf>

Daniel's story

A couple of years after being diagnosed with Alzheimer's disease, Daniel joined a study on cognitive stimulation therapy (CST) at a metropolitan teaching hospital. CST is based on the idea that consistent stimulation of memory, attention, language and other cognitive skills might slow the decline in thinking and memory associated with dementia. Daniel joined a group with eight others who were also living with dementia. Two trained allied health professionals ran these weekly groups.

Although he questioned the reason for attendance each week, Daniel never missed a session. He made friends with another man and they caught the bus together each week. Daniel made a great contribution to the group; he enjoyed hearing what others had to say and sharing his own strategies to assist his declining memory. Daniel saw the group as an exercise program for his brain, saying:

“ It must be useful because it makes me think. ”

When the program came to an end, the occupational therapist referred him to a community gym. Daniel has been going twice weekly for years. He walks to the station and catches the train to the next suburb on his own. He enjoys the gym so much he has recruited several friends to join the gym, and they go for a coffee and a sandwich after each session.



Communicating

Sometimes, after a diagnosis of dementia, communicating can become a little more difficult. Some people revert to a language they spoke in their earlier years.

Poor memory or other thinking skills can interrupt your ability to communicate with others. This can be really upsetting for you, and for the people around you.

If this is the case for you, there are things that can help.

If you're having trouble hearing, an audiologist may be able to organise hearing aids or some other hearing device.

If you're having trouble writing, an occupational therapist might be able to help.

If you're not speaking as well as you once did, or having trouble finding the right word, a speech pathologist can help. They can work with you and with your carers, family and friends to make it easier for you to communicate.

They can also work with you to develop a life book, which is also called a memory book or a chat book. This holds the stories, the photos and the memories that have made you who you are.

And if English is not your first language, you might want to take a worker from your culture, an interpreter or a family member with you to visit the audiologist, occupational therapist or speech pathologist.

Talk to

Speech pathologist

Occupational therapist

Audiologist



Cai's story

For Cai, dementia affects her ability to speak. At times it is distressing, both to her and to her husband Huynh, who cared for Cai while she was living at home. Cai saw a speech pathologist, who used different approaches at different times to support Cai to communicate. At one time, Cai was helped by a word relearning program that she used each day at home on her laptop. Cai also enjoys participating in a choir for people who have trouble communicating. She enjoys the social contact and loves music, so she really gets involved in the singing. Now a memory book has helped Cai settle into new accommodation.

'It has a dozen pages,' says Huynh. 'On the left is a photo and on the right is some text. It is very valuable – it helps her talk about who she is, what her life was like before, and who and what is important to her.'

Eating well

Good food is an important part of life.

It gives you energy, it can bring pleasure, and it can be a way of enjoying the company of family and friends.

But eating well might not be as easy as it used to be. There are ways around this.

SHOPPING

If you find it hard to get to the shops, talk to a dietitian, a social worker or an occupational therapist.

They'll be able to find ways to help, like linking you to local services, setting up online shopping or organising home delivery.

If you have problems finding the foods you like when shopping or knowing which foods are best for you to choose, talk to a dietitian.

If your local shops don't cater for your culture, and you're now finding it harder to get the food you like, talk to a social worker or a dietitian.

It may also help to have a companion with you when shopping to help find things you need more easily. If you don't have a carer or friend to go with you, a dietitian or social worker might be able to put you in contact with community organisations that can help.

Talk to

Dietitian

Social worker

Occupational therapist

COOKING

Many people with dementia find their tastes have changed.

Others find they can't eat as much as they used to, or find it hard to cook for themselves. If this is the case for you, talk to a dietitian or an Aboriginal and Torres Strait Islander health worker. They can work with you to discover what you like, what is easy for you to get and prepare, and how to give yourself the variety you need.

An occupational therapist might suggest some changes to your usual cooking routines, or simpler ways to cook your meals if you are finding it difficult. They might suggest setting up things in your kitchen differently to make cooking safer and easier, like labelling your cupboards to help you remember where things are.

A dietitian can also provide ideas for quick and nourishing meals and snacks. They can also provide quick economic recipes such as one-pot meals and microwave meals for one.

Talk to

Dietitian

Aboriginal and Torres Strait Islander health worker

Occupational therapist

EATING

If you've lost interest in eating, talk to your carer, your family or your friends.

It can be hard to eat alone, and sometimes just sharing a meal helps. Or talk to a dietitian.

They can find ways to keep your strength up.

Some people find it hard to remember to eat. And some people find it hard to hold a knife, a fork, a spoon or chopsticks. If so, an occupational therapist can help. And they can help make sure that where you eat is set up in the best possible way for you.

If you have discomfort with your teeth, gum or dentures, or trouble with keeping them clean, you can call a dental clinic for advice.

If your teeth seem okay but you're having trouble chewing or swallowing, then a speech pathologist can help. They're experts in how the mouth and throat work.

If your mouth is dry, you can talk to a pharmacist about whether or not your medications are playing a part, or talk to the dental clinic about other possible causes.

Talk to

Occupational therapist

Dietitian

Dental clinic

Speech pathologist

Pharmacist



WEIGHT

If you're losing weight and you don't need to, or if you're very overweight, talk to a dietitian.

Once you talk about what and when you eat, they can advise you:

- what food you should be eating and how much
- why these foods are important to you
- ways to improve your appetite and food intake
- high-density nutrition supplements.

An occupational therapist can also help you function more easily at home so you eat the right foods at the right times.

Talk to

Dietitian

Occupational therapist

Yang's story

Yang was hospitalised after a fall at home. Her low weight concerned the hospital staff, so after she was discharged, a dietitian visited Yang at home.

There were many reasons why Yang wasn't eating well. The dietitian made lots of suggestions, which the family took on board. These included:

- arranging more in-home care so Yang could spend more time at home, eating in an environment that was familiar and consistent
- changing the table setting – for example, removing the highly patterned placemats which were distracting Yang
- offering smaller and more nutritious meals
- adding high energy snacks between meals
- adding a high-protein drink two to three times a day.



Speaking up

Many years ago, when you saw a health professional, it was expected that they told you what to do.

But times have changed. You have a right to be treated as an equal, and most health professionals now see you as a partner in your health care.

Modern health professionals understand that it is your life, not theirs. They understand that you know more about yourself than they do. They also understand that you might have a carer, a family member or a friend that you also want to include in discussions and decisions around your health care.

They understand that they should offer you choices or recommendations, but let you decide.

If you speak up for yourself, and work together with doctors, nurses and allied health professionals, there's a good chance that you will get the care and support you want and need.

And if your health professionals don't understand these things and don't treat you as an equal partner in your care, you could show them this booklet, or tell them about the companion booklet written for them, *Better health for people living with dementia: a guide on the role of allied health professionals*. It is available at <https://fightdementia.org.au/about-dementia/health-professionals/allied-health-professionals> or at http://www.aci.health.nsw.gov.au/_data/assets/pdf_file/0004/310837/Better-health-for-people-living-with-dementia.pdf

Or you could speak up to a social worker or other health professional to voice your concerns.

Your voice, your future

Most people would like to have a say in decisions about their future.

You might have already put things in place to make your wishes clear for the future. You might have made a will. You might have appointed someone to manage your finances. And you might have appointed someone to make decisions on your behalf if you ever lose the ability to make your own decisions. You might have talked to your family about advance care planning and the sort of treatment you might want if you are not able to decide for yourself in the future.

If you haven't yet, then it is important to talk to the people closest to you so they know what you want. They can't know if you don't tell them.

A social worker can point you in the right direction about things like appointing someone to make decisions on your behalf and doing an advance care plan. Dementia advisors, Aboriginal and Torres Strait Islander health professionals and other health professionals can too.

Talk to

Social worker

Dementia advisor (NSW and Qld)

Aboriginal and Torres Strait Islander health worker

**National Dementia Helpline
1800 100 500**

Finding your way around the system

There are a lot of services available for people living with dementia and their carers and family.

There may be costs and charges. There may be support payments and concessions available.

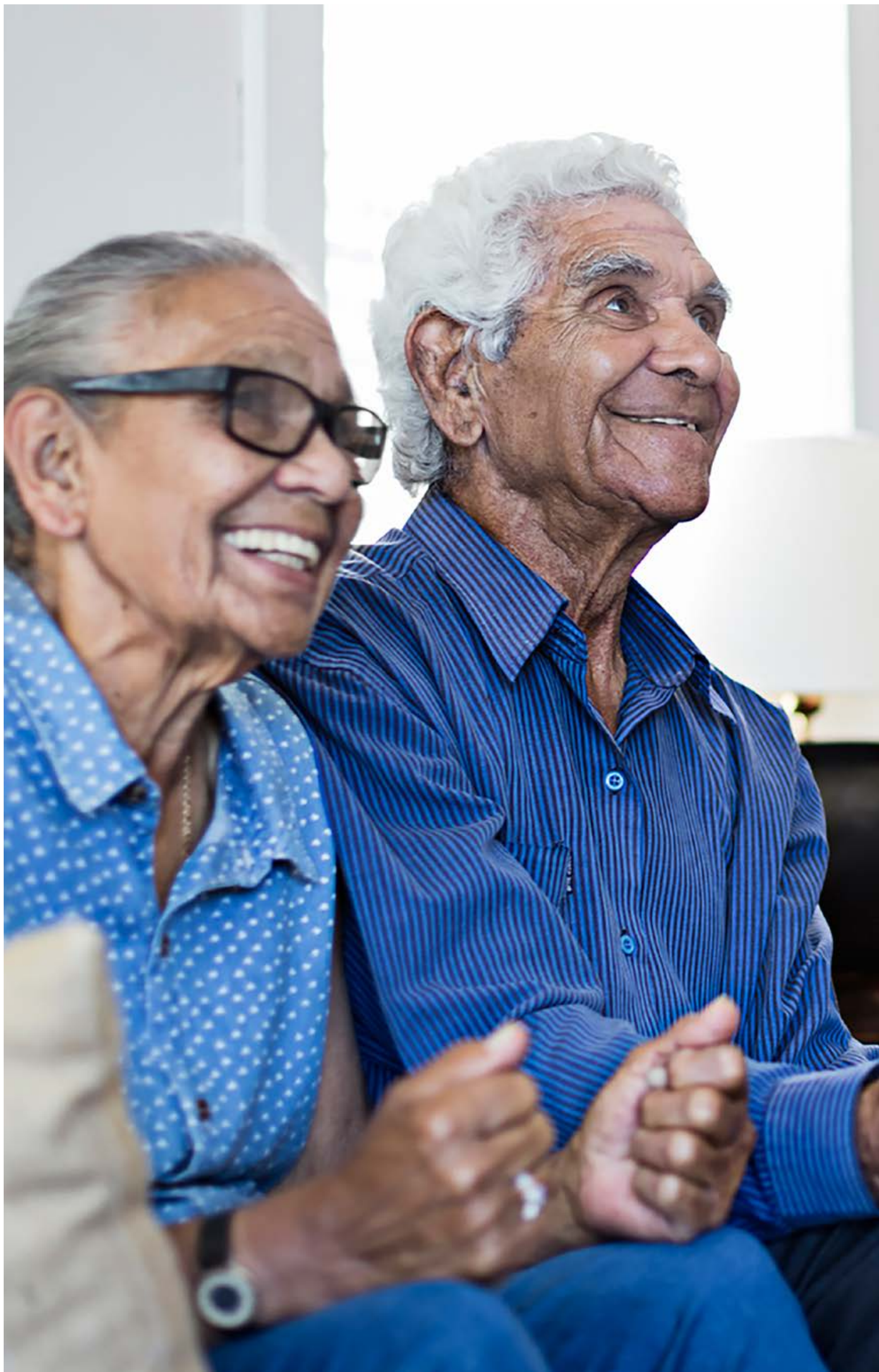
However, it's not easy to understand how health services, community services and aged care services work and fit together. And it's not easy to find the ones that suit you best. It can be difficult to understand all the fees, costs and what support payment and concessions are available.

It is important that you find someone to help you get what you need – it can be a tricky process without someone who knows where to find information. Social workers and dementia advisors are experts on how these systems work. You can also talk to any experienced allied health professional for guidance.

Talk to

Social worker

Dementia advisor (NSW and Qld)



At home with dementia

Your home

Whether you live alone, or with a spouse, carer or family, you want your home to continue to feel like your home, with all the things you've gathered over the years, and all the things you're used to. You also want it to be a safe place to get around in.

If your home is set up the right way, you will find life easier and you will be safer. You may need to make a few changes.

An occupational therapist can look at your home together with you and suggest ways to make it easier for you to do the things you usually do. This might mean making sure that there is enough lighting, that there is enough room to move around your house safely, and that you can find the things you need.

Talk to

Occupational therapist

Kevin's story

Kevin wasn't nicknamed Mr Gadget for nothing. He could turn his hand to anything – he mastered computers, fixed washing machines, put up shelves. He also had a day job; he was a professional man running his own practice. So being diagnosed with Alzheimer's disease at the age of 66 was a big shock for Kevin and his family.

Soon after this diagnosis, an occupational therapist came to the house to work out with Kevin and his wife how they could use his strengths to aid his memory. Mr Gadget had a labelling machine – so they used this to label all the cupboards and shelves to prompt him to put things away in the correct place, and to find them again. He labelled the microwave with step-by-step instructions on how to cook his oats for breakfast each morning, which meant he could continue to do this for himself.

Kevin likes routine and structure; so the occupational therapist worked with Kevin and his wife, Diane, to introduce a weekly timetable of arrangements and activities that Kevin enjoyed; it also gave Diane the time and space to continue her interests and pursuits as a mother, friend and grandmother. The weekly timetable includes a discussion group, a men's lunch group, and going for walks, with friends and family members being included in regular weekly time slots. A big clock with the date as well as the time prompts Kevin to keep track of his timetable.

Help in the home

Getting some help in the home can help you stay in your home for longer.

But it can feel odd to have a stranger in the house. And it can be difficult to ask for help, and to accept that it's needed.

A social worker knows how the system works and what the costs are. They can help you sort out what help you might want, and how to contact the services you need. They can make the calls, too, if you want.

And you can talk to a dementia advisor or other allied health professionals about ways to get the help you need to stay in your home.

The Australian Government website, My Aged Care, also provides information and advice on accessing aged care services, eligibility, assessment and costs. www.myagedcare.gov.au

Talk to

Social worker

Dementia advisor (NSW and Qld)



Moving house

Most people want to stay where they live for as long as possible.

But some people decide to move house. They might move cities to be closer to family, or move into town to be closer to services. They might move to live with a son or a daughter or a friend. They might move to a retirement village.

Thinking about it in advance can make it less stressful.

A family discussion about what's involved in moving might be useful. A social worker can join you to make suggestions; it can be helpful to have someone objective involved.

A counsellor, social worker, psychologist or Aboriginal and Torres Strait Islander health worker can provide emotional support.

An occupational therapist can visit your new home to make sure it will work for you.

Talk to

Social worker

Counsellor

Psychologist

Aboriginal and Torres Strait Islander health worker

Occupational therapist

Medication management

Some people take no medications at all.

Others take quite a few.

It's important that you are only taking medications that help you, and that you aren't taking any that interact with each other.

You can talk to a pharmacist about your medications. They can check why you're taking them and the best time of day to take them. They can work with you and your doctor to make sure you have only the ones you need.

You can talk to an occupational therapist, or your pharmacist, about a system to make sure you take the right medications at the right time.

Talk to

Pharmacist

Occupational therapist

Getting around

If you've been driving a car, you'll want to keep driving for as long as you can. But at some time, that will become difficult.

It's worthwhile talking to someone sooner, rather than later. Then you can plan when to have your driving checked and start finding out about other ways of getting around. An occupational therapist can check how safe it is for you to drive.

A dementia advisor, a social worker or an occupational therapist can talk to you about local transport options, such as public transport, community transport, taxi vouchers and companion cards.

Talk to

Occupational therapist

Dementia advisor (NSW and Qld)

Social worker

Michael's story

When Michael was diagnosed with dementia, he had a specialised occupational therapy assessment of his driving. He passed, and kept driving with an unrestricted licence. He would need to repeat this specialist driving assessment yearly, or sooner if his driving changed.

After some time, his driving skills did change. Michael and his wife decided to downsize to an apartment on the bus route; Michael gave up his driver's license and embraced public transport. He asked to wear an ID band on his wrist, with his name, address and wife's contact details. Two years later, Michael continues to be a keen user of public transport.



Changes to how you think and feel

Changes to how you think and feel

Dementia affects how a person thinks, feels and communicates.

If you can't get across to others what you think and feel, it can be very frustrating and upsetting.

People with dementia sometimes express this frustration and distress through their behaviour. Perhaps the people around you are noticing that your behaviour has changed.

Any changes in behaviour can be confusing for both you and those around you. And it can be hard to know what to do about it.

Neuropsychologists are experts in this area. Occupational therapists and other allied health professionals who specialise in dementia understand what people with dementia are going through, and know about ways to help.

In some parts of Australia, there are teams of allied health professionals who work with you to sort these issues out. The Dementia Behaviour Management Advisory Service (DBMAS) also has allied health professionals; they provide advice and can support carers and families to deal with changed behaviours.

Talk to

Neuropsychologist

Occupational therapist

DBMAS 1800 699 799

Felipe's story

Felipe migrated to Australia with his wife and two children in his mid-fifties. He was a very active man who had played soccer professionally. Felipe worked two full-time jobs – one by day, and one at night – to support his family. After retiring, Felipe stayed very active and took up kayaking in his late seventies. Eventually health problems stopped him keeping up with his exercise and fitness, and he became quite depressed. He then developed dementia.

The combination of depression and dementia hit Felipe very hard. He became forgetful, angry and easily agitated. A dementia service helped Felipe and his family in many different ways, and he improved. He saw the neuropsychologist for assessment and regular counselling to talk through his feelings about the changes.

An interpreter who Felipe had known for some time relayed his 'poetic and philosophical nature' that others couldn't see, as he had lost the ability to express himself freely in English.

A physiotherapist developed a tailored program to build his strength and fitness. An occupational therapist helped him find meaningful activities.

A social worker helped Felipe and his family in making the decision to move to an aged care facility, and provided the practical support to make this happen. Felipe started exercising again and also started watching replays of European football, which he enjoyed. His family was given support and education about communicating with Felipe in different ways. With all these strategies and some medication changes, Felipe's depression improved, and he became fitter and happier again.

Intimacy and sexuality

Some people find that the closeness they have felt with their partner changes. They might need more, or less, conversation, touch, comfort or understanding. Some people find it harder to balance their own needs and the needs of their partner. Their need for physical closeness and their sexual relationship might also change. These changes can be confusing and upsetting for both the person with dementia and for their spouse or partner.

It can be hard to talk about this. But many allied health professionals, as well as some doctors and nurses, understand these changes. Those with experience in counselling, such as psychologists, social workers and counsellors, have been trained in discussing personal matters.

Talk to

Psychologist

Social worker

Counsellor





Carers, families and friends

Most people have someone to turn to, whether you live alone or live with others.

They might be part of your family, they might be friends, they might be part of your community. In health care, these people are often called 'carers'.

The people who care for you are doing so willingly. But they might find they would like some support too. Carers, family and friends of people with dementia often say they need information, emotional support, an opportunity to meet with other carers, and guidance to find their way through the system. And sometimes, they need some time out.

Allied health professionals can help with all of this.

Carer support groups

Carer support groups offer a chance for carers to meet with others in a similar situation, learn from each other and gain skills. Carers sometimes find the connection with other carers carries them through tough times.

Allied health professionals, or your local Alzheimer's Australia organisation, can put the people around you in touch with support groups in your area.

Talk to

Any allied health professional

**National Dementia Helpline
1800 100 500**

Eleanor's story

Eleanor has been caring for her mother since she developed dementia. Eleanor initially lived nearby, visiting often, then moved in with her mum. She is determined to maintain her own life as much as possible, with teaching commitments and time away from home. But there are a lot of restrictions, and she finds it very challenging. She finds the carer support group she attends invaluable, despite being initially sceptical. Part of its value lies in talking to people in similar circumstances and being able to vent feelings without judgement. But it's also seeing that others, too, need time out and need support. On top of that, there are the skills and insights gained from the allied health professional who leads discussions, and from some of the techniques taught at the group, such as meditation.



Time out

Everybody needs time out every now and then. The system refers to it as 'respite'. Respite can be for a few hours, or maybe for a week or two. It can be in your home, or it can be somewhere else. It helps you both, and gives you get a bit of breathing space.

Again, social workers and anybody who regularly works with people with dementia are good people to start with.

Talk to

Social worker

Norma's story

Norma cares for her husband Todd. While she finds it manageable, she needs a break. She's been using two different services, depending on her needs. She can get up to three hours per week respite at home when a carer comes to visit, or she can get more by taking Todd to a respite service for a full day, or even overnight. While she's been using respite intermittently, the respite service has recommended that she take Todd there each Friday to give herself a scheduled break.

“ It is what it is. There's no point wishing it was any other way. But I couldn't do it without respite. ”



Later stages of dementia

Everyone with dementia is different.

The changes in your brain will be happening at a different rate and along a different path to other people with dementia.

Things can continue to change to a point where some people with dementia will require full care.

Whether this care is provided at home or in a residential care facility will depend on you, your carer, your family and your situation.

Transition to residential care

Moving into residential care is a time of change for you and those around you.

Thinking ahead and talking about the possibility of the move can be helpful. So can getting information and support for you and your family. It can prepare you for a move and help you to adjust to the change.

There are many health professionals who can help. They may work in aged care assessment teams, community services, aged care facilities or hospitals. They can give you information, help with practical tasks and give emotional support.

Dementia advisors and social workers can talk with you and give you information about what needs to happen and the paperwork involved.

Counsellors, psychologists and social workers can provide emotional support and counselling to you and your carer to talk through feelings, like loss and grief.

My Aged Care also provides information and advice on accessing aged care services, eligibility, assessment and costs. www.myagedcare.gov.au

Talk to

Dementia advisor (NSW and Qld)

Social worker

Counsellor

Psychologist

Social worker



End of Life

Some people find it hard to think about the end of life; others like to talk about it upfront.

The choices you and your family make about end of life are very personal choices. Your choices can be written down in an advance care plan, which may be called different things in different states and territories.

If you plan to be cared for at home, your family and carers will need support from medical, nursing, allied health and community services to provide the care you'll need. Health professionals can help you think this through, and make it happen when the time comes.

Occupational therapists and other health professionals can give information to help you and your family make the decision about whether to care for you at home. Occupational therapists can assess your needs and those of your carers, provide or point you towards equipment, and train carers to use it.

Social workers provide emotional support and guidance, and liaise between services and health professionals.

Physiotherapists can give advice about maintaining mobility and movement and train carers to provide safe assistance.

Dietitians have a role in providing expertise about food and nutrition and where to get nutrition supplements if needed.

Speech pathologists can assess and provide advice about changes to your swallowing. They can also help your carers understand changes in communication to ensure that you can continue communicating in the best way possible.

Talk to

Occupational therapist

Social worker

Physiotherapist

Dietitian

Speech pathologist

What allied health professionals do



What allied health professionals do

Everyone with dementia is different.

There are many different types of allied health professionals.

This section lists many of them and how they might be able to work with you. Not all will be available everywhere. Some work in local health organisations, some in community and aged services and some work in private practice. Some charge fees and others don't; some are subsidised by government and others aren't. Please ask.

An Aboriginal and Torres Strait Islander health worker has very broad skills and cultural knowledge. If you're Indigenous, they can provide health care and support, and can help you find your way around the health care and the aged care systems.

National Aboriginal and Torres Strait Islander Health Worker Association

Tel: 1800 200 800 or 02 6221 9220

<http://www.natsihwa.org.au/>

An audiologist can assess your hearing and help you hear more clearly. They can arrange a hearing aid, talk to you about other hearing devices and work alongside you while you adapt to your hearing aids.

Audiology Australia

Tel: 03 9877 2727

<http://audiology.asn.au/>

A Chinese medicine practitioner works in traditional Chinese medicine using acupuncture, herbal remedies or both.

Chinese Medicine Board of Australia

Tel: 1300 419 495

<http://www.chinesemedicineboard.gov.au/>

A chiropractor's focus of practice is the structure of the spine and how it relates to function and your overall health.

Chiropractors Association of Australia

Tollfree: 1800 075 003

Tel: 02 8844 0400

<http://chiropractors.asn.au/>

A counsellor can meet with you to talk through specific problems such as adjusting to change and the feelings arising from that, such as loss and grief. The aim is to foster wellbeing.

Psychotherapy and Counselling Federation of Australia

Tel: 03 9486 3077

<http://www.pacfa.org.au/>

A dementia advisor offers assistance through education, counselling, referrals and providing resources. They work in services that specialise in working with people with dementia and their carers. Most dementia advisors are allied health professionals or nurses. Dementia advisors are available in NSW and Queensland; other states and territories may have allied health professionals doing a similar role, with a different title.

Dental therapists, dental hygienists and oral health therapists

all work alongside dentists to help you keep your mouth, teeth and gums in good condition. They can work with you to maintain good oral health.

Dental Hygienists Association of Australia

<http://www.dhaa.info/>

A dietitian is a specialist in food and nutrition. They aim to keep you well nourished and can help with any problems you may have with eating or maintaining a good weight. They are also the best people to advise on any nutrition supplement products, if needed, and where to get them.

Dietitians Association of Australia

Tel: 02 6189 1200

<http://daa.asn.au>

A diversional therapist designs leisure and recreation programs. They get to know about you, your history, your interests, your passions and your culture. Then they can suggest activities that are stimulating and enjoyable, either by yourself or with others.

Diversional Therapy Australia

Tel: 02 9887 5035

<http://diversionaltherapy.org.au/>

An exercise physiologist can work with you to improve your fitness, strength and balance.

Exercise and Sports Science Australia

Tel: 07 3171 3335

www.essa.org.au

A music therapist can support you by using music to improve health, functioning and wellbeing.

Australian Music Therapy Association

Tel: 03 9525 9625

<http://www.austmta.org.au/>

A neuropsychologist is a psychologist with expertise in how changes in your brain can lead to changes in thinking, memory and behaviour. They work with you and your family to help you find strategies to adapt to the changes in your brain.

Australian Psychological Society

Toll free: 1800 333 497 Tel: 03 8662 3300

<http://www.psychology.org.au/>

An occupational therapist will focus on the things you do every day, like eating, sleeping, dressing and showering. They also look at things you like doing when you are out and about, like driving, and things you do with others, like socialising. They can help you work out what your skills and abilities are, and what help you might like to be able to do the things that are important to you. They can also help you adapt your home environment and use technology to stay at home longer and more safely.

Occupational Therapy Australia

Toll free: 1300 682 878

Tel: 03 9415 2900

<https://www.otaus.com.au/>

An optometrist can check your eyesight and check for eye conditions. They can organise glasses if you need them. If you need it, they can refer you to an eye specialist.

Optometry Australia

Tel: 03 9668 8500

<http://www.optometry.org.au/>

An osteopath can offer treatment and advice to help improve mobility, circulation and balance, helping you lead a more fulfilling life.

Osteopathy Australia

Tel: 1800 467 836

<http://www.osteopathy.org.au/>

A pharmacist can check whether you are taking the right medications or not, and work with you and your doctor to make sure you are only taking medications that really help.

The Pharmacy Guild of Australia

Tel: 02 6270 1888

<http://www.guild.org.au/>

A physiotherapist can help you improve your strength, balance and the way you move around. They can also help with muscle and joint problems and help reduce any pain or stiffness. They can teach carers and family the safest way of providing physical assistance to you.

Australian Physiotherapy Association

Tel: 1300 306 62

<https://www.physiotherapy.asn.au/>

A podiatrist can check the health of your feet, advise you about footwear and assist you to manage foot discomfort and injuries. They are part of the allied health team that keeps you mobile.

Australian Podiatry Council

Tel: 03 9416 3111

<http://www.apodc.com.au/>

A psychologist is an expert in understanding human behaviour. They can provide counselling and can help you and those around you deal with emotionally difficult issues, and adjust to loss and change.

Australian Psychological Society

Toll free 1800 333 497

Tel: 03 8662 3300

<http://www.psychology.org.au/>

A social worker works to understand how you fit into the world around you. They provide support during times of stress and are experts in practical support with things like money and accommodation. They can give you information about appointing others to make decisions on your behalf. Many social workers are also trained counsellors and can support you through times of change, loss and grief.

Australian Association of Social Workers

Tel: 02 6199 5000

<http://www.aasw.asn.au/>

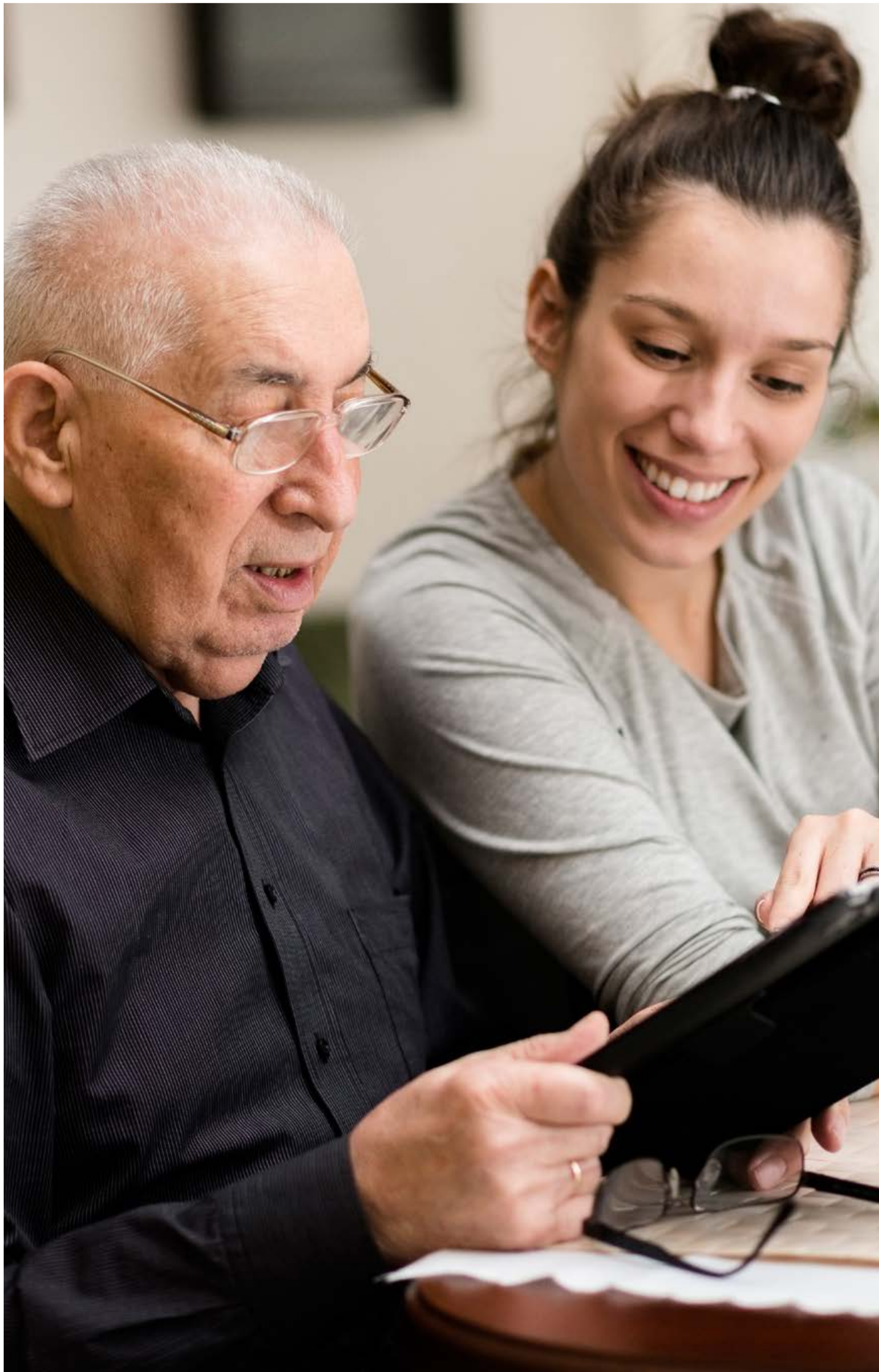
A speech pathologist is an expert in speech, language and communication, and can help you communicate with others if speaking has become difficult. They can also help with any issues you might have in swallowing.

Speech Pathology Australia

Tel: 1300 368 835 or 03 9642 4899

<http://www.speechpathologyaustralia.org.au/>

Finding an allied health professional



Finding an allied health professional

You can find an allied health professional through national contacts, professional associations or local contacts.

National contacts		
National Dementia Helpline	1800 100 500	Talk to someone about dementia and find the help you need
My Aged Care	1800 200 422	The Australian Government's advice line for older people
	http://www.myagedcare.gov.au/help-home/allied-health-support	Information on allied health and a link to finding an allied health professional near you
	http://www.myagedcare.gov.au/caring-someone	Information for carers, and a link to counselling
Carer Gateway	1800 422 737	Detailed information for carers
	https://www.carergateway.gov.au/	
Carers Australia	1800 242 636	The national peak body for carers provides advocacy, information, advice and counselling for carers
	http://www.carersaustralia.com.au/	
Dementia behaviour management advisory service	1800 699 799	A 24-hour service that provides family and carers of a person with dementia with support, advice and strategies on how to cope with changed behaviours
Healthdirect	1800 022 222	A 24-hour health advice line
	http://www.healthdirect.gov.au/health-topics	Information about allied health professionals
National Health Service Directory	http://www.nhsd.com.au	Search for some allied health professionals near you

Professional associations

Every allied health discipline has a national professional association. These are listed in the section 'What allied health professionals do'. Many of those websites have a 'how to find' button so you can find an allied health professional by postcode.

Local contacts

COMMUNITY HEALTH CENTRES AND HOSPITALS

Local health services in each state and territory have information about their local allied health staff and may also be able to link you to private allied health professionals.

YOUR GP

Many GP clinics employ allied health professionals. If not, your GP may be able to refer you to one locally. Ask your GP about a GP management plan, which provides a Medicare rebate for all or part of the fee of an allied health professional in private practice for a set number of sessions.

YOUR PRIMARY HEALTH NETWORK

Go to the Primary Health Network map locator at <http://www.health.gov.au/internet/main/publishing.nsf/Content/PHN-Locator> and find the phone number and web address of your Primary Health Network. Contact them to find an allied health professional.

OTHER WAYS TO FIND AN ALLIED HEALTH PROFESSIONAL

Local newspapers and publications, internet search engines and the Yellow Pages may also list local allied health professionals.

Resources

Alzheimer's Australia

Alzheimer's Australia has information, resources, programs, DVDs, publications, and events for people living with dementia and their families and carers. There are branches in each state and territory, and programs in many metropolitan, regional and rural areas.

Helpsheets that address the topics in this booklet are available at the Alzheimer's Australia website. <https://fightdementia.org.au/>

You can call the National Dementia Helpline on 1800 100 500 and ask for information to be sent to you.

You can contact the Alzheimer's Australia Library and Information Service; each state branch holds many books and DVDs for people with dementia and their carers. You can sign up to the library's blog to keep up to date with new resources and research. Go to <http://alzheimersnswlibrary.blogspot.com.au/> or talk to the librarian via the helpline.

Alzheimer's Australia runs programs for people living with dementia, their families and carers. They include the Living with Dementia program, carer support groups, counselling, education and social activity-based groups. For further information contact the helpline.

Living with dementia

The Alzheimer's Australia Living with Dementia program provides people in the early stages of dementia, along with their families and carers, with a program of information, advice and peer support to help them to come to terms with their condition and plan for the future.

Carer support groups

Alzheimer's Australia carer support groups provide an environment in which carers of people with dementia can discuss issues with other people in a similar situation.

Family carer education

Alzheimer's Australia's skilled educators offer specialised dementia education sessions and programs for family members and carers of people living with dementia.

Counselling

Alzheimer's Australia provides a free counselling service for people with dementia, their families and friends.

Public awareness activities

Throughout the year, Alzheimer's Australia delivers a range of seminars and other presentations to the community on memory loss and dementia-related subjects.

Social activity programs

Alzheimer's Australia offers a variety of social activity-based groups for people with dementia and their carers. These groups provide an opportunity for social interaction and peer support. Offerings vary depending on your location. To find out what social activity-based groups are offered where you live, contact the helpline or your state branch.

The following pages list other resources and programs and the websites from which they can be reached. They are organised under the chapter headings of this booklet.

Being yourself and adjusting to change

Engage, Enable, Empower. A website for people living with dementia. Alzheimer's Australia. <http://livingwellwithdementia.org.au/>

Resources for Aboriginal and Torres Strait Islander Communities. Alzheimer's Australia. <https://fightdementia.org.au/about-dementia/resources/aboriginal-and-torres-strait-islander>

Resources for culturally and linguistically diverse communities. Alzheimer's Australia. <https://fightdementia.org.au/about-dementia-and-memory-loss/resources/CALD>

Understanding Dementia. A Massive, Open, Online Course (MOOC). Wicking Dementia Research and Education Centre, University of Tasmania. Free, 9-week course for people living with dementia, carers and professionals. <http://www.utas.edu.au/wicking/wca/mooc>

Your health and wellbeing

Choose health: be active – a physical activity guide for older Australians. 2014. Australian Government.

Connections matter: helping older people stay socially active. 2014. Beyond Blue. <http://resources.beyondblue.org.au/prism/file?token=BL/1366>

Dementia: communication. 2014. Better Health Channel, Victorian State Government. May 2014. <https://www.betterhealth.vic.gov.au/health/conditionsandtreatments/dementia-communication>

Dementia and nutrition in the home, Discussion paper 14, November 2015. Alzheimer's Australia NSW. https://nsw.fightdementia.org.au/files/NSW/documents/Discussion_Paper-Dementia_and_Nutrition_in_the_Home.pdf

Eating well: a nutrition resource for older people and their carers. 2015. Nutrition Services, Central Coast Local Health District. <http://www.cclhd.health.nsw.gov.au/ourservices/nutrition/Documents/EatingWellResource.pdf>

Eating well with dementia. 2015. Department of Health and Human Services, Tasmania. https://www.dhhs.tas.gov.au/_data/assets/pdf_file/0017/202049/Eating_Well_with_Dementia.pdf

Eating well with dementia: a carer's guide. 2014. Nutrition and Diet Resources UK. www.gov.scot/resource/0044/00449379.pdf

Family and friends matter: how to stay connected to a person living with dementia. 2013. Alzheimer's Australia. <https://fightdementia.org.au/sites/default/files/NATIONAL/documents/Family-and-friends-matter.pdf>

Heart Foundation Walking. Find a local walk at <http://walking.heartfoundation.org.au/>

Move more, sit less. Australia's physical activity and sedentary behaviour guidelines for adults. 2014. Australian Government. [http://www.health.gov.au/internet/main/publishing.nsf/Content/F01F92328EDADA5BCA257BF0001E720D/\\$File/brochure%20PA%20Guidelines_A5_18-64yrs.PDF](http://www.health.gov.au/internet/main/publishing.nsf/Content/F01F92328EDADA5BCA257BF0001E720D/$File/brochure%20PA%20Guidelines_A5_18-64yrs.PDF)

Personal life history booklet. 2011. Produced for the study 'Developing and testing a strategy to enhance a palliative approach and care continuity for people who have dementia', led by Alzheimer's Australia WA. <http://www.caresearch.com.au/caresearch/portals/0/documents/whatispalliativecare/NationalProgram/PCDementiaCOP/copd1-personal-life-history-booklet-final.pdf>

Speech pathologists working with older people. Speech Pathology Australia. http://speechpathologynq.com.au/wp-content/uploads/2014/08/Factsheet_Speech_Pathologists_Working_With_Older_People.pdf

The brainy app. An app to raise awareness of the risk factors for dementia and to help you be brain healthy. Download app from: <http://www.yourbrainmatters.org.au/a-little-help/brainyapp>

The benefits of physical activity and exercise for people living with dementia. Discussion paper 11, November 2014. Alzheimer's Australia NSW. <https://nsw.fightdementia.org.au/nsw/news/the-benefits-of-physical-activity-and-exercise-for-people-living-with-dementia>

Tips and ideas for older Australians: Australia's physical activity and sedentary behaviour guidelines. 2014. Australian Government. [http://www.health.gov.au/internet/main/publishing.nsf/Content/health-publth-strateg-phys-act-guidelines/\\$File/Tips&Ideas-Older-Aust-65plus.PDF](http://www.health.gov.au/internet/main/publishing.nsf/Content/health-publth-strateg-phys-act-guidelines/$File/Tips&Ideas-Older-Aust-65plus.PDF)

Your brain matters: an Alzheimer's Australia program to maximise brain health. <http://www.yourbrainmatters.org.au>

Your shed and dementia: A manual. 2014. Alzheimer's Australia NSW. <https://fightdementia.org.au/files/NATIONAL/documents/Mens-Shed-Dementia-Manual.pdf>

Speaking up

Advance Care Planning Australia. This national site has links to your state or territory. Some state and territory websites have information specifically for Aboriginal and Torres Strait Islander people. <http://advancecareplanning.org.au/>

Dementia Advocates Program, Alzheimer's Australia. If you are a person with a diagnosis of dementia or a current or former carer of a person with dementia, you can join the Dementia Advocates Program.

NSW: <https://nsw.fightdementia.org.au/nsw/support-us/dementia-advocates-program>

WA: <https://wa.fightdementia.org.au/wa/support-us/become-a-dementia-advocate>

Dignity in Care. 2015. UK. <http://www.dignityincare.org.uk/>

Future planning and advance care planning: why it needs to be different for people with dementia and other forms of cognitive decline. 2016. Cognitive Decline Partnership Centre and Hammond Care. http://sydney.edu.au/medicine/cdpc/documents/resources/J000606_CDPC_report2015Final_WEB.pdf

Preventing financial abuse of people with dementia. Discussion paper, 10 June 2014. Alzheimer's Australia NSW. <https://nsw.fightdementia.org.au/files/20140618-NSW-Pub-DiscussionPaperFinancialAbuse.pdf>

Start to talk. A website about planning ahead. <http://start2talk.org.au/>

What prevents people with dementia making plans for their future? Discussion paper 4, March 2012. Alzheimer's Australia NSW. <https://nsw.fightdementia.org.au/files/20120328-REP-DiscussionPaper4.pdf>

At home with dementia

Assistive technology: prompts and reminders. Alzheimer's Australia WA. <https://wa.fightdementia.org.au/wa/about-dementia-and-memory-loss/resources/resources-wa/assistive-technology-product-information-sheets/prompts-and-reminders>

At home with dementia: a manual for people with dementia and their carers. 2011. NSW Family and Community Services: Ageing, Disability and Home Care. https://www.adhc.nsw.gov.au/_data/assets/file/0011/228746/at_home_with_dementia_web.pdf

Dementia enabling design website. Alzheimer's Australia. For information, tools and advice on dementia design. www.enablingenvironments.com.au

Dementia-friendly home app. 2016. Alzheimer's Australia Vic. This tablet app provides you with ideas to make the home more accessible for people living with dementia. <https://vic.fightdementia.org.au/vic/about-dementia-and-memory-loss/resources/resources-to-download-vic/dementia-friendly-home-app>

Driving and dementia: a decision aid. 2014. University of Wollongong. <http://smah.uow.edu.au/nursing/adhere/drivingdementia/index.html>

Driving – each state and territory branch of Alzheimer's Australia has information about driving in that state, and links to state and territory-based organisations. <https://fightdementia.org.au/search/node/driving>

Independent Living Centres Australia. For information about assistive technology, call 1300 885 886 or go to website <http://ilcaustralia.org.au/> to be directed to the centre for your state and territory. Or download the handbook **Helpful handbook for memory loss: products, equipment, information, advice.** 2015. Independent Living Centre NSW. https://www.ilcnsw.asn.au/home/publications/publications#pub_HB_MemoryLoss

Changes to how you think and feel

A guide for family carers: dealing with behaviours in people with dementia. 2014. Dementia Collaborative Research Centre: Assessment and Better Care and the University of New South Wales. www.dbmas.org.au/uploads/resources/A_Guide_for_Family_Carers.pdf

Dementia Behaviour Management Advisory Service. 24-hour helpline: 1800 699 799 or <http://dbmas.org.au/contact/>

Intimacy and sexual issues, Helpsheets 19. 2012. Alzheimer's Australia. https://fightdementia.org.au/files/helpsheets/Helpsheet-CaringForSomeone19-IntimacyAndSexualIssues_english.pdf

Carers, families and friends

National Dementia Helpline. 1800 100 500.

Alzheimer's Australia. A telephone information and support service available across Australia for people with dementia, their carers, families and friends.

Carers Australia, 1800 242 636. The national peak body for carers provides advocacy, information, advice and counselling for carers. <http://www.carersaustralia.com.au/>.

Carer Gateway, 1800 422 737. This is the Australian Government's gateway providing practical information for carers. <https://www.carergateway.gov.au/>

Support for carers: a practical guide to services for families and friends of people with dementia. 2015. Alzheimer's Australia. <https://fightdementia.org.au/sites/default/files/NATIONAL/documents/Support-for-carers.pdf>

Working carers gateway. <http://www.workingcarers.org.au/index.php>

Later stages of dementia

Planning for the end of life for people with dementia. Paper 23, part one. March 2011. A report for Alzheimer's Australia by Professor Colleen Cartwright. https://fightdementia.org.au/files/20121009_US_23_Planning_for_the_end_of_life_Part_one.pdf

Planning for the end of life for people with dementia. Paper 23, part two. May 2011. A report for Alzheimer's Australia by Professor Colleen Cartwright. https://fightdementia.org.au/files/20121009_US_23_Planning_for_the_end_of_life_Part_two.pdf

The most difficult decision: dementia and the move to residential aged care. Discussion paper 5. 2012. Alzheimer's Australia NSW. https://nsw.fightdementia.org.au/sites/default/files/20121016-NSW-PUB-Moving_To_Res_Care.pdf

Acknowledgements

Steering committee

Co-Chairs		
Elaine Todd	Consumer Dementia Research Network	Alzheimer's Australia
Jamie Hallen	Co-Chair, Allied Health sub-group	Aged Health Network, ACI
	Senior Physiotherapist, Aged Care Service in Emergency Teams	Prince of Wales Hospital, South Eastern Sydney Local Health District
Members		
Jacqueline Wesson	Occupational Therapist, Aged Care Psychiatry Service	Prince of Wales Hospital, South Eastern Sydney Local Health District
	Research Occupational Therapist	Falls, Balance and Injury Research Centre, Neuroscience Research Australia
Jenny Henderson	Consumer Dementia Research Network	Alzheimer's Australia
Joan Jackman	Consumer Dementia Research Network	Alzheimer's Australia
Kate Swaffer	Consumer Dementia Research Network	Alzheimer's Australia
Michelle Frawley	Occupational Therapist	
	Outgoing Co-Chair, Allied Health Sub-Group	Aged Health Network, ACI
	Network Manager	Acute Care, ACI
Viki Brummell	Social Worker	
	Co-Chair	Aged Health Network, ACI
	Network Manager	Aged Care and Rehabilitation Services Clinical Network Hunter New England Local Health District

Special thanks to:

- the people living with dementia and their carers, including members of the Consumer Dementia Research Network, who have provided constant and valuable input into the scope, content and structure of this publication; and a special thanks to those who shared their stories (names have been changed).
- the allied health sub-group of the Aged Health Network, ACI, for their discipline-specific input, guidance and reviewing of this publication.

Funding

- This initiative is funded by the Alzheimer's Australia National Quality Dementia Care Initiative with support from J.O. & J.R. Wicking Trust.

About this booklet

The publication has been developed by the Allied Health Sub-group of the Aged Health Network, Agency for Clinical Innovation. It has been funded by Alzheimer's Australia National Quality Dementia Care Initiative with support from J.O. & J.R. Wicking Trust. The publication has been developed by allied health professionals, people living with dementia and their carers and families.

It has drawn information from many sources, including Australian national guidelines, Alzheimer's Australia's numbered papers, discussion papers and fact sheets, and international research.



**UNDERSTAND ALZHEIMER'S
EDUCATE AUSTRALIA**

For information and advice contact the
National Dementia Helpline on:

1800 100 500

The National Dementia Helpline is an Australian Government funded initiative.