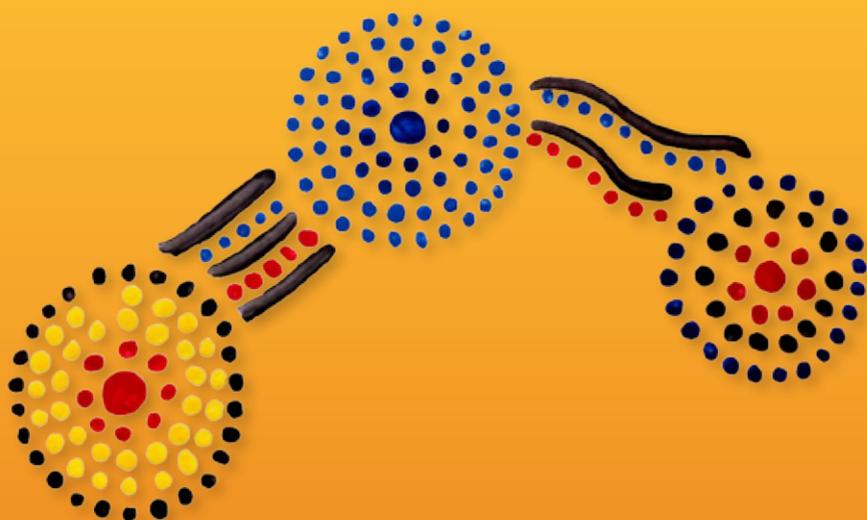


Family, friends and community



Acknowledgements

We acknowledge the traditional Custodians of Country throughout Australia and their continuing connection to land, sea and community. We pay our respect to them and their cultures, and to the elders both past and present.

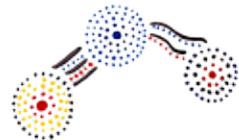


We would like to thank the following groups who participated in consultations about this resource:

- Koori Yarning Carers Group
- Bundjalung Elders Group
- Bunjum Families NSW Mothers' groups
- Worimi Community Elders
- Global Village Creativity Centre representatives
- Illawarra Aboriginal Corporation Elders Group

Cover artwork created: by an Aboriginal artist (anonymous)

This painting represents Dementia Australia NSW Division's relationship with both traditional and urban Aboriginal communities.



The large blue area represents Dementia Australia, while the blue dots within the travelling lines represent the flow of information and understanding into the communities, the red dots symbolises the flow of cultural understanding and awareness back into Dementia Australia which then changes the colour of Dementia Australia's Aboriginal services and supports.

The painting is depicted in the shape of a boomerang, which symbolises the importance of the return of information back to the community.

The content of this booklet has been developed from *Family and Friends Matter* © 2015, funded by the Australian Government Department of Social Services, and *Look after your brain – a guide to dementia for Aboriginal people* 2012 compiled by Ageing Disability and Home Care, Department of Family and Community Services.

This booklet is for information purposes, it does not provide medical advice.

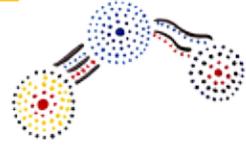
This publication has been funded by Family & Community Services

Photographs pages 2 and 13 © Alamy

Photograph page 8 © iStock Images

Photographs pages 4, 6 and 14 © Gary Radler





Contents

Introduction	2
Family, friends and community	3
When someone you care for finds out they have dementia	5
Dementia Facts	6
When someone has dementia they might...	9
Helpful things to remember	10
Communication	12
Tips for making the most of your visit	15
Where to go for help	16

Introduction

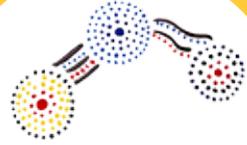
Family, friends and community are important. They help us all get through life's ups and downs.

- What can we do to keep this special bond when a family member or friend is living with dementia?
- How do we stay connected in ways that are meaningful?
- What interests can we continue to enjoy together?

These are some of the important questions this booklet aims to address.

Please share the information contained in this booklet with family members.





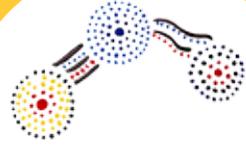
Family, friends and community

- Family members, friends and community accept you as you are.
- They listen.
- They are there for you.
- You can share things with them that you might not share with others.
- They show you respect.
- They are links to the past and the future.

Family, friends and community play an important part in our lives and this is especially true for people living with dementia.

Changes will occur because of dementia, but it is vital that relationships with family, friends and community are supported and encouraged.





When someone you care about finds out they have dementia

Family and Friends of people living with dementia are often shocked to learn their relative or friend has dementia, even when they thought something was wrong.

“It stressed me a lot; we’ve been friends for such a long time.”

One family member said they did not really know what dementia means, what its symptoms are or how it would progress.

Another said they felt sorry and wondered “How can I help? What can I do? What should I do?”

When someone finds out they have dementia they may feel:

- Sad
- Confused
- Anxious
- Embarrassed (shame)
- Frustrated
- Angry
- Frightened

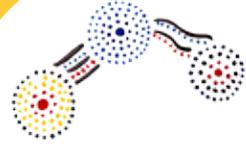
***“We can let them know we still love them
and we’re always here for them.
We’re not pulling away”***

– Elder

Dementia facts

- Dementia is a disease of the brain that makes it difficult to remember, think and plan.
- Over time the person's dementia will get worse and they may find it harder to keep doing things they used to do.
- Aboriginal and Torres Strait Islander people are at a higher risk of developing dementia and often up to ten years earlier than non-Aboriginal and Torres Strait Islander people.
- There are over 100 different types of dementia. Alzheimer's disease is the most common cause of dementia.
- Other types of dementia include vascular dementia, frontotemporal dementia and Lewy body disease.





- Many people have a combination of two different types of dementia, such as Alzheimer’s disease and vascular dementia; this is known as mixed dementia.
- Dementia can happen to anybody. Not all older people get dementia, but older people are more likely to get dementia than younger people.
- Dementia can affect people in their 30s, 40s and 50’s.
- If someone you know shows signs of dementia it’s important that they get it checked out by a doctor. It is better to get treatment as early as possible so the person and their family can manage things more easily.
- There is support available for the person living with dementia, their families and friends. This support can make a real difference to the quality of life of those living with dementia. See “where to go for information or help” at the end of this booklet.

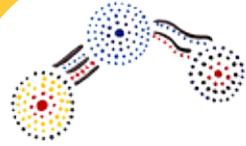
***“Dementia is not a disease
you can catch”***

– Community member

***“Family is key for the person
with dementia”***

– Elder





When someone has dementia they might:

- go for a walk and forget where they're going or where they've been
- feel worried
- not want to go out, or visit friends and family, or do the things they used to do
- find it hard to solve problems
- feel something isn't quite right with their brain
- get cranky and say things they wouldn't have before
- forget things they have already said
- ask the same question over and over
- have trouble doing the shopping properly
- have trouble paying bills and handling money properly
- have trouble looking after themselves
- eat more than usual or forget to eat
- forget to take medications

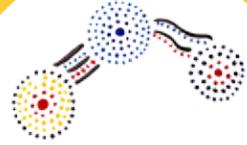
Adapted from Look after your brain

Helpful things to remember

- People living with dementia are trying very hard to make sense of their world.
- Accept that the person living with dementia will forget things – possibly even your name – however, that doesn't mean they have forgotten what you mean to each other.
- It is important to let people know we still love them and are here for them even if they don't appear to understand.
- Be patient. They are not being difficult on purpose. When the person living with dementia says the same thing over and over, tells the same story or asks the same question it is like the first time for them. The person may not remember you have talked about this before and it could be something they think is important for you to know.
- Acknowledge the feelings behind the words and show respect.
- Understanding and support are what the person needs.
- Keep the environment as positive as possible.
- Try not to upset them.

***“In this community respect for
the elders is number one”***

– Elder



- Focus on the person they are now and not on the dementia.
- Contact with others helps a person to feel important and that they have value.
- People who are caring for the person need support and time for themselves. It's important that they care for themselves too.
- You can still share interests with the person, but you may do this in a different way.
- Simply being with the person living with dementia can be comforting for both of you. Gentle touching, such as holding hands, linking arms or giving a hug are ways of showing affection without words.

***“Respect – This is our traditional culture.
This is who we really are as
Aboriginal people”***

– Elder

COMMUNICATION

Communication is important to help us maintain who we are and our connections to others.

Here are some tips for talking with people living with dementia.

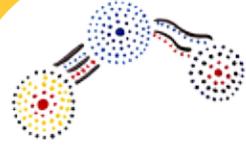
- Always acknowledge the person living with dementia first, not the carer, family member or friend. Don't prejudge their level of understanding.
- Respect the person's dignity.
- Greet the person with a smile, introduce yourself and get their attention.
- Speak clearly.
- Talk about one thing at a time and provide information in small chunks.
- Use humour.
- Use simple direct questions to help the person recall events without making them feel embarrassed that they can't remember or by focusing on their memory.

For example, instead of asking "do you remember?" say:

"I really liked the movie we watched at elders group yesterday."

"I'm looking forward to your brother John's visit this evening."

"It was so lovely that your granddaughter Sarah made this card for you."



- Turn off the TV or radio to reduce background noise. Noise can make it hard for the person to focus on what’s happening.
- Try to speak slowly, with just one person talking at a time.
- Be patient, give the person time to find an answer. Prompt them if needed.
- Don’t talk down to the person.

“Speak from the heart”

– Elder



Communication (continued)

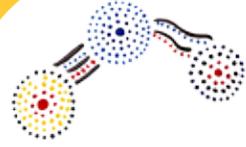
- Make your time together meaningful.
- Consider their interests.
- Involve the person as much as possible.

Remember that activities together can be simple and fun:

- They can be everyday tasks such as gardening or cooking.
- They can encourage reminiscing – storytelling, looking at photos or pictures, listening to music.
- They can be short - even just five minutes.
- They can include everyone in the family and community.
- Doing nothing together is still doing something!
- An activity is worth doing even if the person does not remember it.

Being together is what matters most.





Tips for making the most of your visit

- Be relaxed, be yourself.
- Keep it simple.
- Keep things to the person's "normal".
- Be flexible – things may not go to plan.
- Don't rush things. The person may need time to work out who you are and why you are there. Give prompts, don't make the person struggle.
- Choose a quiet, familiar place.
- Chat about or do one thing at a time.
- Don't argue.
- Be kind to yourself; some visits may leave you feeling sad.
- Keep your emotions calm during the visit. If you get upset, talk to someone you trust afterwards.

“My sister was a ballroom dancer, so when we visited we played music for her and she would move in time to it”

– Elder

Where to go for more information or help

Aboriginal Medical Service (AMS)

Look up the address of your local AMS on the Aboriginal Health and Medical Research Council website: www.ahmrc.org.au or call 02 9212 4777 (business hours)

Dementia Australia (Formerly Alzheimer's Australia)

Advocates for the needs of people living with all types of dementia and provides support services, education and information.
www.dementia.org.au

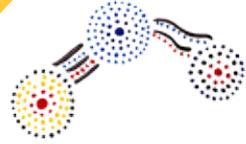
National Dementia Helpline 1800 100 500

The National Dementia Helpline is for anyone living with or interested in finding out more about dementia.

The Helpline operates nationally from 9.00am to 5.00pm Monday to Friday excluding public holidays.

It's a free confidential phone, email and online information and support service which provides:

- information about dementia and memory loss
- information about government support services (including My Aged Care, the Carer Gateway, Centrelink)
- information about services in your area
- emotional support to help you manage the impact of dementia
- information on how you may be able to reduce the risk of getting dementia



Email address: helpline.nat@dementia.org.au

Webchat address: www.dementia.org.au/helpline/webchat/

Your GP

Your local hospital

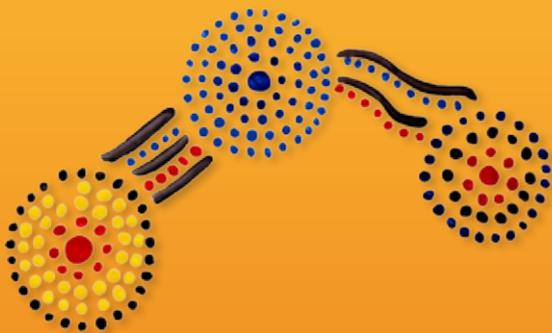
For information about planning ahead, such as:

- Advanced Care Directives
- Enduring Power of Attorney
- Guardianship

Call 1 800 100 500 or look at [www.dementia.org.au/planning ahead](http://www.dementia.org.au/planning-ahead)

***“It’s okay to ask
for help!”***

– Elder



dementia
australia™

National Dementia Helpline 1800 100 500
dementia.org.au