

# Family, friends and community

Being together is  
what matters most.



## Acknowledgements

Dementia Australia would like to acknowledge the Aboriginal and Torres Strait Islander people as the traditional custodians and carers of the country of Australia. We acknowledge and respect the Aboriginal and Torres Strait Islander people of Australia's relationship with country and their cultural and spiritual beliefs.

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**For further information and enquiries please contact:**

National Dementia Helpline  
**1800 100 500**

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**[dementia.org.au](https://www.dementia.org.au)**

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**Aboriginal and Torres Strait Islander people are advised that this booklet may contain images of deceased people.**



# Introduction

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

When someone has dementia, family and friends can help to:

- keep the special bond you share
- stay connected to community in meaningful ways
- continue to enjoy common interests together.

This booklet features information, tips and strategies on staying connected to people living with dementia. **Please share this booklet with family and friends.**



## **Someone who has dementia might:**

- go for a walk and forget where they're going or where they've been
- feel worried
- not want to go out, 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.

# Family, friends and community

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.

Family members, friends and community are important because:

- they 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.



“

**It stressed me a lot;  
we'd been friends for  
such a long time. ”**



# 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.

One family member said they did not really know what “dementia” meant, what the symptoms were 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.

# Dementia facts

Everyone experiences dementia differently, meaning that the symptoms and how they progress are different for each person.

- Dementia is a disease of the brain that may make it difficult to remember, plan and perform everyday tasks.
- Over time, the person's dementia will get worse and they may find it harder to keep doing things they used to do.

“

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

– Elder

- Aboriginal and Torres Strait Islander people are at a higher risk of developing dementia – often up to 10 years earlier than non-Aboriginal and Torres Strait Islander people.
- There are more than 100 different types of dementia. Alzheimer’s disease is the most common type of dementia.
- Other types of dementia include vascular dementia, frontotemporal dementia and Lewy body disease.
- 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 50s.
- 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 people 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 more 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

# Understanding dementia and providing support

When someone is living with dementia:

- they are trying hard to make sense of their world
- they may forget things – possibly even your name – but that does not mean they have forgotten what you mean to each other.

You can support them in the following ways:

- Let them know you still love them and are there for them, even if they don't seem to understand.
- Be patient. People with dementia are not being difficult on purpose. When they tell the same story over and over or repeat the same question, for them it is like saying it for the first time. The person may not remember you have talked about this already and it could be something they think is important for you to know.
- Acknowledge the feelings behind the words and show respect.
- Keep the environment as positive as possible.

- If the person with dementia is upset, see if you can discover what might be distressing them and whether you can distract and calm them.
- Focus on the person and not on the dementia.
- Maintain contact and encourage family and friends to do so too. It will help someone with dementia feel important and that they have value.
- People who are caring for the person with dementia need support and time for themselves. It's important that the carers 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.

“

**In this community respect for the Elders is number one. ”**

– Elder

“

**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 keep our connections with others.

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

- Always acknowledge the person and greet them with a smile.
- When you have their attention, introduce yourself.
- Don't prejudge their level of understanding.
- Respect their dignity.
- Speak clearly.
- Talk about one thing at a time and provide information in small chunks.
- Use humour.
- Help the person recall events without making them feel embarrassed if they can't remember. For example, instead of asking "do you remember?" say:  
"I really liked the movie we watched at Elders' group yesterday." or  
"I'm looking forward to your brother John's visit this evening." or  
"It was so lovely that your granddaughter Sarah made this card for you."





- Noise can be distracting. If possible – and it’s not going to upset the person who has dementia – either turn off the TV or radio, or turn the volume down.
- Try to speak slowly, with just one person talking at a time.
- Be patient, give the person time to find an answer.

“

**Speak from the heart. ”**

– Elder

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

**Activities together can be simple and fun,  
for example:**

- You can do everyday tasks such as gardening or cooking.
- You can encourage reminiscing – storytelling, looking at photos or pictures, or listening to music.
- Activities can be short – even just five minutes.
- They can include everyone in the family and community.
- Doing nothing and being together is still doing something.
- An activity is worth doing, even if the person with dementia 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 and that's okay.
- The person with dementia may need time to work out who you are and why you are there. Help by giving them prompts and allow time for them to orient themselves to you and their surroundings.
- Choose a quiet, familiar place.
- Chat about or do one thing at a time.
- Be kind to yourself: some visits may leave you feeling sad.
- Try to be calm and not get upset during the visit. If you do get upset, talk afterwards with someone you trust.

**“ 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 Aboriginal Medical Service and other Aboriginal and Torres Strait Islander health services:

[naccho.org.au/naccho-members](https://naccho.org.au/naccho-members)

## National Dementia Helpline

The National Dementia Helpline is a free telephone service that provides information and advice to:

- people living with dementia
- people concerned about changes to memory and thinking
- people living with mild cognitive impairment
- family, friends and carers of people living with dementia
- people who work in health and aged care.

In addition to sharing information and advice, the helpline team can also:

- provide emotional support and guidance
- connect you to community support, services and programs

- discuss government support, including My Aged Care, National Disability Insurance Scheme (NDIS), Carer Gateway and Dementia Behaviour Management Advisory Service (DBMAS).

## **How to access the National Dementia Helpline**

Free call: **1800 100 500**

Webchat: [dementia.org.au/webchat](https://dementia.org.au/webchat)

Email: [helpline@dementia.org.au](mailto:helpline@dementia.org.au)

The National Dementia Helpline operates 24 hours a day, seven days a week, 365 days a year.

If you require the assistance of an interpreter, please call the Translating and Interpreting Service on **131 450**.

If you are deaf or have a hearing or speech impairment, please call the National Relay Service on **133 677**.

## **Your local doctor (GP)**

## **Your local hospital**

“

**It's okay to ask for help!** ”

- Elder



## About Dementia Australia

Dementia Australia is the source of trusted information, education and services for the estimated half a million Australians living with dementia, and the almost 1.6 million people involved in their care.

We advocate for positive change and support vital research. We are here to support people impacted by dementia, and to enable them to live as well as possible.

Founded by carers more than 35 years ago, today we are the national peak body for people living with dementia, their families and carers. We involve people impacted by dementia and their experiences in our activities and decision-making, to make sure we are representative of the diverse range of dementia experiences. We amplify the voices of people impacted by dementia through advocating and sharing stories to help inform and inspire others.

No matter how you are impacted by dementia or who you are, we are here for you.

# National Dementia Helpline

## 1800 100 500



For language assistance  
call **131 450**

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