Dementia Australia®

Family and friends matter

How to stay connected with a person living with dementia

This booklet features information, tips and strategies on staying connected to people living with dementia. Please read and share it with your family, friends and carers. The information in this booklet has been based on input and discussions with people impacted by dementia.

We acknowledge and are grateful for each contributor generously sharing their time, experience and knowledge.

It is important to remember everyone living with dementia is unique. The content in this booklet is general in nature and we recommend you seek professional advice in relation to any specific concerns or issues you may have.

For further information and enquiries please contact:

National Dementia Helpline
1800 100 500

Find us online
dementia.org.au

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Introduction

Family and friends matter. They help us navigate life's ups and downs. They accept us as we are. If your family member or friend has been diagnosed with dementia, it's natural to feel unsure about what this means for the future.

In this guide, you'll find answers to questions like:

- How will dementia impact our relationship?
- What can we do to keep a special bond?
- How can we stay connected in meaningful ways?
- What interests can we continue to enjoy together?

If you're living with dementia, please consider sharing this booklet with family and friends.

"Ordinary human beings can be very understanding if they know how to react and how their actions can support another."

- Hennell & Hennell, n.d.

Family and friends

If you are a family member or friend of someone living with dementia, you play an essential role in their lives.

- You support them on their journey.
- You listen without judgement.
- You respect them and accept them as they are.
- You provide a link to their past and their future.

While dementia may cause some things to change over time, important elements of the relationship can still remain.

One thing that doesn't change is their need to be a valued member of a family or circle of friends. In fact, this may be the time they need you – as their family or friend – the most.

Instead of focusing on what the person can't do, it can help to focus on the things you can still enjoy together.

It is easier to cope with dementia in someone for whom we care if we give full value to the person that they are now rather than fretting endlessly over what is no longer possible.

- Crisp, 2000

When someone you care about is diagnosed with dementia

If your friend or family member has been diagnosed with dementia, you may feel shock, anger or denial. For many people, it can also come as a relief as they "suspected something was wrong."

It's important to remember that the person with dementia is bound to have plenty of powerful feelings, too. They may experience:

- loss
- sadness
- confusion
- anxiety
- embarrassment
- fear
- frustration
- anger
- paranoia.

It's important to be there for the person with dementia and maintain a good relationship with them. At times, your connection may be put to the test. It's important to stay connected, support each other and talk about how dementia is impacting the way you feel.

Putting yourself in their shoes and making peace with the new chapter of your relationship can help.

Dementia facts

What is dementia?

- Dementia affects the brain and may make it difficult to remember, plan and perform everyday tasks.
- Dementia is a term that describes a large group of illnesses and conditions that cause a progressive decline in a person's functioning. There are over 100 different types of dementia.
- Many people have more than one type of dementia; this is known as mixed dementia.
- Alzheimer's disease is the most common form of dementia. Other forms of dementia include vascular dementia, frontotemporal dementia and Lewy body disease.
- Every person with dementia is unique. The symptoms and progression of dementia can vary in different people.
- Symptoms often begin slowly and gradually becoming worse over time.

Who gets dementia?

- The risk of dementia increases with age but is **not** a normal part of ageing.
- Three in 10 people over the age of 85 and almost one in 10 people over 65 have dementia[1]. It can also affect younger people.

Is there a cure for dementia?

- There is no cure for dementia. However, medications and some alternative treatments have been found to relieve certain symptoms for some people.
- Dementia Australia offers support to people living with dementia, as well as their families and friends.

1 The National Centre for Social and Economic Modelling NATSEM (2016) Economic Cost of Dementia in Australia 2016–2056

Common signs and symptoms of dementia

Common signs and symptoms of dementia could include changes to:

- **Memory** – such as not being able to recall recent events or information.
- **Language** – such as problems finding the words to describe or name things.
- **Wayfinding skills** – such as difficulty finding the way to familiar places like the local shop.
- **Planning** – such as being unable to organise tasks like making a shopping list.
- **Sequencing** – such as difficulty doing things in a particular order, like making a cup of tea or getting dressed.
- **Knowledge** – such as being unable to recall and apply stored knowledge (for example, how to count money).
- **Emotions** – such as appearing to be less interested and connected, or more anxious.
- **Insight** – such as being genuinely unaware of their behaviour and its consequences, despite clear evidence to the contrary.

Simon and Bradley

“About three years ago I began to notice changes in him that were hard to explain. In our social group he would come out with something totally off the topic, as though he was not tuned in properly.

The diagnosis of frontotemporal dementia explained his behaviour, the forgetfulness and confusion. He’s only in his early 40s, so it was a shock.

At first, while he was still at home, I did what we had always done; dropped in for a coffee and a chat. Now he is in the nursing home I go as often as I can manage and we play cards – Simon’s version of the game – or we go for a walk. Simon the person, my friend, is still there.”

Helpful tips

- People living with dementia are working very hard to make sense of their world – to see through the confusion and deal with their symptoms.
- Putting yourself in their shoes can help you, as family and friends, to understand and be more accepting.
- Don't take mistakes and mix ups personally they are due to a person's confusion.
- Feelings of confusion, grief and loss, and even anger, are normal feelings caused by dementia.
- The person with dementia may forget your name but they will remember that they like you.
- If the person with dementia appears difficult it is not deliberate.
- Don't 'test' the memory of the person with dementia or feel you need to correct mistakes. Try entering their world and agreeing with them; or gently reassure or redirect them if they become agitated.
- Remind yourself that what a person needs at this time is understanding and support
- Support the person in the caring role to take a break.

When things change

- The person with dementia may have forgotten about some of your shared interests and memories, but they're still the same person.
- Try to focus on the person they are now and respect what they are dealing with.
- Connection with others is still important to them. You can help them maintain a sense of identity and worth. How you behave towards a person can be a powerful reminder to the person of their role in your life and the value of that role to you.
- While your interactions with the person with dementia may change over time, you can still enjoy common interests in different ways.
- Simply being with the person with dementia can be comforting for both of you.
- Over time, the person with dementia may need more reassuring human contact. Hold their hands, link arms or offer a hug.

Communication and connection

Communication is essential for maintaining our identity and connecting us to others. The content of your everyday exchanges may be relatively unimportant. What counts is its role in connecting us together.

Language skills and vocabulary can diminish as dementia progresses but the desire to communicate does not. People continue to want to understand and be understood. You can keep the communication going even when it feels one-sided.

The person with dementia may forget details of recent events, or the event itself. This is not an indication of indifference or lack of significance; it is simply one of the major impacts of dementia.

You can help the person recall these events without feeling embarrassed by using helpful prompts.

For example:

“I really enjoyed our drive around the lake yesterday.”

“I am looking forward to John’s visit this evening.”

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

Good communication tips for talking to people with dementia

- Talk to the person, not the carer, family member or friend.
- Greet the person with a smile and get their attention.
- Make eye contact and use body language. This becomes even more important when language diminishes.
- Speak clearly.
- Express one idea at a time and provide information in small chunks.
- Use simple, direct questions such as "wasn't it lovely when we went out to the park yesterday?"
- Don't offer too many choices.
- Remove distractions such as noise and bright lights.

- Be patient, don't rush, and allow the person time to find the right answer.
- Don't prejudge the person's level of understanding.
- Don't take the person literally.
- Use humour.
- Use clear and simple language.
- Don't argue or confront.
- Respect the person's dignity.

Maintaining interests

Spending quality time is not about what you do, but how you are doing it together. You can help the person you care for stay involved in everyday activities, so they feel productive and able to contribute.

There are 3 P's when spending time together:

1. **Pleasure** – you both enjoy the time
2. **Participation** – you both get involved as much as possible
3. **Presence** – you show you want to be with the person.

Remember:

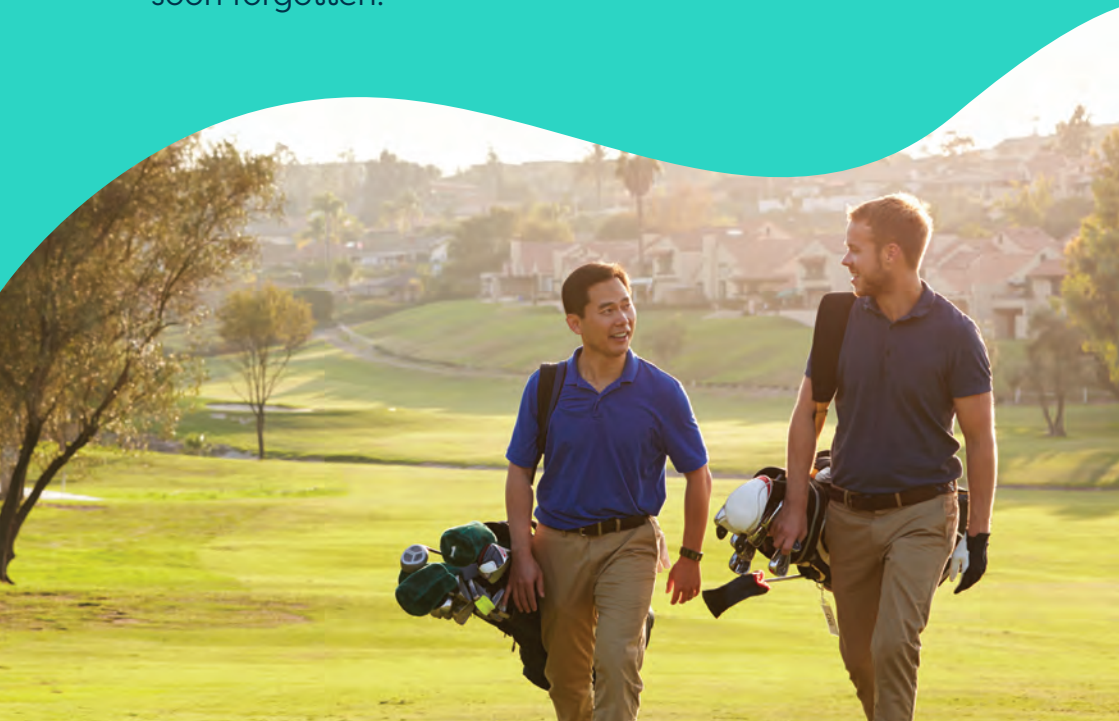
- Any simple activity can be a positive experience.
- Past hobbies and skills from working lives can be good starting points when thinking about something to do together.
- You might be surprised which activities work well. Try not to rule anything out prematurely.

Activities:

- don't have to be long – they may only last five minutes
- work best when the person is happy to participate
- need to be age appropriate
- including young adults and children can work well
- that stimulate the senses can bring pleasure.

Keep in mind:

- Doing nothing together can actually be doing something.
- An activity is still worthwhile even if it is soon forgotten.



Different levels of participation

Just because a person living with dementia can no longer do things as independently as before, doesn't mean they're not interested. You can still help them play a part.

Here's an example of how a simple, pleasurable activity like making biscuits can have a role for everyone. From doing the whole activity to watching and listening, there's always a way to involve the person with dementia.

Making biscuits:

1. **I can initiate, plan and complete all aspects**

   Able to decide on what kind of biscuits. Can plan, buy the ingredients, follow the recipe, successfully prepare and cook the biscuits.

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2. **I can do it all if someone sets it up**

   Able to make the biscuits once the ingredients are set out and recipe is explained by another person.

3. **I can do some part of it**

   Can either measure, mix or shape biscuits, depending on ability.

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4. **I can do it if someone shows me**

   Able to repeat each step with prompts and help.

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5. **I can watch and monitor**

   Able to tell you if the biscuits look right, or listen for the oven clock to ring.

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6. **I can talk about it**

   Able to talk about their own experiences of making biscuits.

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7. **I can critique**

   Able to taste biscuits and provide feedback.

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8. **I can watch and listen**

   Able to watch and listen while you make the biscuits.

- Adapted from Bell & Troxell, 2001, p.204

Mum and her sister, Louise

"Mum's sister, Louise, told me she felt very upset when visiting as she had no idea if Mum actually knew her anymore. Mum had quite advanced dementia. She was showing little recognition and could not communicate verbally.

Mum and my aunt had both enjoyed having dinner parties and sharing recipes. I suggested to my aunt that she try a short, morning visit and take in a few interesting cooking magazines. Mum really enjoyed this visit. She smiled and pointed at the pictures. It was a great relief as they were very close and I didn't want my aunt to be upset and stop visiting Mum."

Experiences you can share with your friend or family member

- Go for a drive.
- Attend a religious service.
- Eat an ice cream.
- Practice golf at a driving range.
- Go to a small outdoor market.
- Visit a mutual friend.
- Have a coffee in a quiet cafe.
- Sit on the veranda, or sit in the park.
- Watch the birds.
- Walk the dog.
- Reminisce, look at photos.

- Read the newspaper together.
- Fold the washing, or tidy up a drawer.
- Plant seeds, water the flowers, visit a nursery.
- Visit a quiet gallery.
- Kick a ball.
- Make a cup of tea, squeeze oranges to make fresh juice.
- Sort coins or stamps.
- Make and write cards.
- Watch television, listen to the cricket on the radio.
- Play music and sing favourite songs.
- Do a simple quiz or puzzle together.
- Recite poetry.
- Hand sand a piece of wood.
- Enjoy a massage.
- Brush each other's hair.
- Cook a BBQ together.
- Bake biscuits.
- Make a collage from cut out pictures.
- Play with a grandchild together.

The best way of all to help someone with dementia is to stay interested, stay in touch and let them know they are loved.

Tips for making the most of your visit

- Be relaxed, be yourself and avoid forced cheerfulness.
- Have a flexible attitude. Things may not go to plan, and that's okay.
- Accept that you may have to initiate conversation and things to do.
- Take something with you to share.
- Establish a visiting routine: say hello and introduce yourself.
- As you leave ask if you may visit again, smile and wave.
- Don't rush things. The person may need time to register who you are and why you are there.
- Remember that silence is not necessarily a negative thing.
- Choose a quiet, familiar location and introduce one thing at a time.
- If possible, visit the person regularly, even for a brief time.
- While your visit may not be remembered, it was enjoyed at the time.
- Be kind to yourself; it's possible some visits may leave you feeling sad.

Sonya and Claire

“She is the most important person in my professional life. And we are good friends as well. Now my admiration for her also comes from watching her cope with this disease. We still share a friendship and I still respect her enormously. I’m going to try taking something to read to her on my next visit because she has always had such a curious mind, a great love of books and discovery. It is something we continue to share.”

“I can’t change the person with dementia but I can change my response.”

References

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Note: Most of the above resources can be accessed through Dementia Australia's national library service.

About Dementia Australia

Dementia Australia is the source of trusted information, education and services for the more than 400,000 Australians living with dementia, and the more than 1.5 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 40 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**

Find us online
dementia.org.au

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