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

Family and friends matter

How to stay connected to a person living with dementia
We would like to acknowledge the people who contributed to the development of this book and those friends of the project who shared their stories with us. Names and other identifying personal details have been changed.

Disclaimer:
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Family and friends matter. They help us navigate life’s ups and downs. They accept us as we are.

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

These are some of the important questions this booklet aims to address. We hope the information and suggestions in this guide help you stay connected, as you discover different and meaningful ways to be with a person living with dementia.

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

Family and friends

- Close family members and friends 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 invaluable links to the past and the future.

Family and friends play an important part in our lives. The need to be a valued member of a family or circle of friends does not diminish with dementia.

In fact, the chances are that this is when we need our family and friends most. Yet, often the fear of the unknown, or the changes that we see, interfere with our ability to continue with the relationship as we knew it.

Changes will occur as a result of dementia, but important elements of the relationship still remain.

“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, p.12)
When someone you care about is diagnosed with dementia

Friends of people living with dementia have reported feeling “terribly shocked” to learn of their relative or friend’s diagnosis or that they “suspected something was wrong.”

“It stressed me a lot; we’ve been friends for such a long time.” One friend said they did not really know what dementia meant, did not know the symptoms of the disease or how it would progress. Another expressed feeling at a loss: “I don’t know how to help”.

Feelings are powerful for the person with dementia too. They may experience:

- Loss
- Sadness
- Confusion
- Anxiety
- Embarrassment
- Fear
- Frustration
- Anger
- Paranoia

Any of the above feelings is a normal part of any relationship and can test the connection between family and friends. However, if you’ve had a good relationship, you’ll miss having this person in your life and later on you might regret not having kept in touch.
Dementia facts

- Dementia is a broad term which describes a collection of symptoms that are caused by disorders affecting the brain.

- Dementia may affect thinking, communication, memory, behaviour and the ability to perform everyday tasks.

- Every person with dementia is unique and the symptoms and progression of dementia may present differently in different people.

- Dementia is a disease process that is progressive and irreversible.

- Risk increases with age but is NOT a part of normal ageing. It is more common at 65 years and over, with 1 in 10 people having dementia, increasing to 3 in 10 over the age of 85\(^1\), but it can also affect those in their 30s, 40s and 50s.

- Alzheimer’s disease is the most common cause of dementia. Many people have more than one type of dementia; this is known as mixed dementia.

- Other dementias include vascular dementia, fronto-temporal dementia and Lewy body disease.

- There is no cure for most causes or forms of dementia; however, medications and some alternative treatments have been found to relieve certain symptoms for some people.

- Support is available for the person with dementia, their families and friends. This support can make a positive difference to the quality of life of those living with dementia.

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\(^1\) The National Centre for Social and Economic Modelling NATSEM (2016) 
Economic Cost of Dementia in Australia 2016-2056 p.6

Dementia Australia
## Common signs and symptoms of dementia

These may include changes to

<table>
<thead>
<tr>
<th>Category</th>
<th>Example</th>
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<tbody>
<tr>
<td>MEMORY</td>
<td>not being able to recall recent events or information</td>
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<tr>
<td>LANGUAGE</td>
<td>problems finding the words to describe or name things</td>
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<tr>
<td>VISUO-SPATIAL SKILLS</td>
<td>difficulty finding the way to familiar places like the local shop</td>
</tr>
<tr>
<td>PLANNING</td>
<td>being unable to organise tasks such as making a shopping list</td>
</tr>
<tr>
<td>SEQUENCING</td>
<td>difficulty doing things in a particular order, such as making a cup of tea or getting dressed</td>
</tr>
<tr>
<td>KNOWLEDGE</td>
<td>being unable to recall and apply stored knowledge like how to count money</td>
</tr>
<tr>
<td>EMOTIONS</td>
<td>appearing to be less interested and connected, or perhaps more anxious</td>
</tr>
<tr>
<td>INSIGHT</td>
<td>being honestly unaware of their own behaviour and its consequences, despite clear evidence to the contrary</td>
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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 things to remember

• People living with dementia are working very hard to make sense of their world, to see through the confusion and deal with their symptoms.

• Being prepared to ‘walk a mile in their shoes’ can help family and friends understand and be more accepting.

• Don’t take personally mistakes and mix ups due to a person’s memory loss.

• 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.

• 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.

• It may be possible for more family members to be involved in supporting the person with dementia.

(Adapted from Bell & Troxell, 2002, A Dignified Life, pp.20, 95 and “I’ll get by with a little help from my friends” Information for friends of people with dementia Alzheimer’s Scotland).
When things change

- The person living with dementia may forget some of the shared experiences and interests you have both enjoyed. But, despite dementia, the essential part of the person survives.

- Focus on the person they are now and respect what they are dealing with.

- Remember that contact with others helps 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, the essentials of the interests you shared can survive.

- Simply being with the person with dementia can be comforting for both of you. You may find that, more and more, the person with dementia needs the reassurance of human contact.

- Gentle touch – such as holding hands, linking arms or a hug is likely to become more important.

(Crisp, 2000, p.5)
Communication and connection

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

By using prompts, you can help the person recall these events without making them feel embarrassed that they can’t remember or by focusing on their memory.

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, it 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, 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.
Interests

The art of spending time with a person living with dementia is not what is done but doing it together. Being involved in everyday activities helps everyone feel productive and able to contribute.

There are 3 P’s when spending time together:

1. Pleasure – that you both enjoy the time.
2. Participation – that you both get involved as much as possible.
3. Presence – that 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.
- Activities we think will never work sometimes do.

Activities:
- may only last five minutes.
- work best when the person participates willingly.
- need to be age appropriate.
- including young adults and children may 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 cannot do things as independently as they once did does not mean they are not interested. They can still play a part. Here is an example where a simple, pleasurable activity such as making biscuits includes a role for everyone, from the person who can do the whole activity by themselves to the person who can simply watch and listen.

Making biscuits:

I can initiate, plan and complete all aspects
Able to decide on kind of biscuits, able to plan, buy ingredients, can follow the recipe and successfully prepare and cook the biscuits.

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.

I can do some part of it
Can either measure, mix or shape biscuits depending on ability.

I can do it if someone shows me
Able to repeat one step with prompting and help.

I can watch and monitor
Able to tell you if the biscuits look right, listen for the oven clock to ring.

I can talk about it
Able to talk about own experiences of making biscuits.

I can critique
Able to taste biscuits.

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 to 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 favorite 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
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.
• 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, and desirable, visit with some regularity, 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.
“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.”
References

The National Centre for Social and Economic Modelling
NATSEM (2016) Economic Cost of Dementia in Australia 2016-2056 p.6

Alzheimer Scotland. (2003). I’ll get by with a little help from my friends: Information for friends of people with dementia
Lochaber, Author.
https://www.alzscot.org/assets/0001/7435/Friends_Booklet_lo-res.pdf

Health Professionals Press.


NOTE: Most of the above resources can be accessed through your local Dementia Australia Library.
“I can’t change the person with dementia but I can change my response.”
About DEMENTIA AUSTRALIA

Dementia Australia is the national peak body and charity representing people with dementia, their families and carers.

Dementia Australia manages a wide range of innovative national programs to deliver services such as provision of information, support, advocacy, counselling, training and education to people with dementia, their families and carers as well as to professionals working in the dementia field.

Our aim is for dementia-friendly communities where people living with dementia are supported to live a high quality of life with meaning, purpose and value.

For more information about our services and to find out how you can help us, visit dementia.org.au or call the National Dementia Helpline 1800 100 500

dementia.org.au

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