

**“It’s hard enough losing your memory and abilities without losing your friends as well”**



# **FRIENDS MATTER**

**How to stay connected to a friend living with dementia**

**UNDERSTAND ALZHEIMER'S  
EDUCATE AUSTRALIA**

# UNDERSTAND ALZHEIMER'S EDUCATE AUSTRALIA

This booklet has been adapted from the *Friends and Companions* workshop - a project undertaken by Alzheimer's Australia Vic which was generously supported with funding from a Trust.

We would like to acknowledge the following people who contributed to the development of this book: Linda Gordon, Denise Wissman, Kath Harper, and those friends of the project who shared their stories with us. Names and other identifying personal details have been changed.

#### Disclaimer:

This booklet is for information purposes. The booklet does not purport to provide medical advice. Alzheimer's Australia and its employees are not liable for any error or omission in the information provided.

© Lynton Crabb Photography: photos p1, 2, 5, 14, 19  
Other photos: istockphoto

ISBN 978 1 921570 42 1

© 2012 Alzheimer's Australia Vic ABN 14 6 71 840 186

# CONTENTS

Introduction	3
What makes a <b>good</b> friend?	4
When a friend is diagnosed with dementia	5
Dementia facts	6
Common signs and symptoms of dementia	7
Helpful things to remember	9
When things change	10
Communication and connection	11
<b>Do's</b> and <b>Don'ts</b> for good communication	12
Interests	13
Different levels of participation	15
Interests to experience with your friend	17
Tips for making the most of your visit	18
References	back flap
About Alzheimer's Australia	back cover
Are you a good friend to someone living with dementia?	inside back flap





# INTRODUCTION

**Friendships matter. Friends help us navigate life's ups and downs. Friends accept us as we are.**

What can we do to maintain this special bond when a 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 friend living with dementia.

**“Even when my friend became unsure of my exact name, she still had a sense of my basic identity as a much-loved and ‘very important person’. These were her own words during my last visit to her in reply to a passer-by who asked who I was.”**

*(Crisp, 2000, Keeping in Touch with Someone who has Alzheimer's, p4)*

# WHAT MAKES A GOOD FRIEND?

- A **good** friend accepts you as you are (is non-judgemental)
- A **good** friend listens
- A **good** friend is there for you
- You can share things with a **good** friend that you might not share with others
- **Good** friends respect each other as equals

We can probably count on one hand our really good friendships and the qualities, such as those above, that make them so important to us. The need for these close and special friendships does not diminish because a disease process occurs. In fact, the chances are that this is when we need our friends most. Yet, often the fear of the unknown, or the changes that we see, interfere with our ability to continue with the friendship as we knew it.

Changes will occur as a result of dementia, but important elements of the friendship 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, p12)

# WHEN A FRIEND IS DIAGNOSED WITH DEMENTIA

Friends of people living with dementia have reported feeling, 'terribly shocked' to learn of their 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 friends. However, if you've had a good friendship, you'll miss having your friend in your life and later on you might regret not having kept in touch.



# DEMENTIA FACTS

- Dementia is a broad term which describes a loss of memory, intellect, social skills and what could be considered normal emotional reactions.
- Every person with dementia is unique and the progression of dementia will be different for everyone.
- 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 (1 in 4 people aged 85+ have dementia) but it can also affect those in their 30s, 40s and 50s.
- Alzheimer's disease is the most common form of dementia and accounts for between 50% and 70% of cases.
- Other dementias include vascular dementia, fronto-temporal lobar degeneration, Lewy body disease and alcohol-related dementia (Korsakoff's syndrome).
- There is no cure for most 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.



# COMMON SIGNS AND SYMPTOMS OF DEMENTIA

These may include changes to

Example

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

**“We cannot abolish their symptoms, but we can lessen the effects and help to make their life more worth living”**

(Crisp, 2000, p8)



## 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 fronto-temporal lobe 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' will help overcome denial and gain acceptance.
- 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.
- Let your friendship remain a relaxed relationship without the emotional overtones of family interactions.
- Remind yourself that what a person needs at this time is a really good friend.
- Be, when possible, a friendly visitor to the person's loved one or carer.
- Your friend may forget your name but they will remember that they like you.

(Bell & Troxell, 2002, A Dignified Life, pp20, 95).

**“It can simply mean being there for them as a friendly presence, still giving attention to and responding to each other.”**

(Crisp, 2000, p8)

# WHEN THINGS CHANGE

- A friend 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 your friend may change over time, the essentials of the interests you shared can survive.
- Simply being with a friend is a pleasure because of their familiar, comforting presence. You may find that, more and more, the friend living with dementia needs the reassurance of human contact.
- Even if your relationship with your friend was not physically demonstrative, you may find that gentle touch – holding hands, linking arms, or a hug – becomes more important.

(Crisp, 2000, p5)

# 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.

Your friend 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 your friend recall these events without making them feel stupid or by focussing 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.'*



# DO'S AND DON'TS FOR GOOD COMMUNICATION

The following basics of good communication do work.

**Do's** for good communication:

- Keep language simple
- Use repetition
- Ask one question or make one statement at a time
- Use positive language (for example, 'let's enjoy the moment')
- Do most of the work, help fill in blanks but don't take over
- Use good timing by matching your conversational pace to your friend's and be alert to signs of fatigue
- Use humour
- Remember body language and non-verbal communication (for example your tone of voice) become even more important when language diminishes.

**Don'ts** for good communication:

- Don't take the person literally
- Don't offer too many choices
- Don't argue or confront
- Don't talk down to the person
- Don't talk about the person as if they were not there
- Don't ask questions that require remembering too much
- Don't give information too far in advance.



# INTERESTS

The art of maintaining interests is not what is done; it is in **the doing together**. Maintaining interests 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 that:

- Interests are everywhere.
- They can tap into past hobbies and skills from working lives.
- Those we think will never work sometimes do.
- They may only last five minutes.
- Activities should be voluntary.
- They should be adult in nature.
- Ones that include young adults and children may work well
- Activities need to be initiated by others.
- Those that stimulate the senses bring pleasure.

## And another thing to keep in mind:

- Doing nothing together can actually be doing something.





# 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 in doing these things. They will still be able to play a part.

Here is an example where a simple, pleasurable interest 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 be**

Able to watch and listen while you make the biscuits

(Adapted from Bell & Troxell, 2001, *The Best Friends Staff*, p204)



## MUM AND LOUISE

*'Mum's oldest friend, Louise, told me she felt awkward 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.'*

*One of the things Mum and Louise had enjoyed doing was going on a cruise together and re-living their travels. I suggested to Louise that she try a short, morning visit and take in a few interesting travel brochures. Mum really enjoyed this visit. She smiled and pointed at the pictures. It was a great relief as the friendship was a central part of both their lives.'*

# **INTERESTS TO EXPERIENCE WITH YOUR FRIEND**

**Go for a drive** Sit in the park 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 **Watch the birds** Walk the dog Look at photos Read the newspaper together Fold the washing **Plant seeds** Visit a quiet gallery **Kick a ball** Make a cup of tea Sort coins or stamps **Squeeze oranges to make fresh juice** Make and write cards **Watch TV** Listen to the cricket on the radio **Play music and sing** Reminisce **Do a simple quiz or puzzle together** Sing favourite hymns and songs **Recite poetry** Hand sand a piece of wood **Enjoy a massage** Tidy up a drawer Brush each other's hair **Cook a BBQ together** **Visit the nursery** Bake biscuits Water the flowers

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. Your friend 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 last 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”**

# Are you a good friend to someone living with dementia?

Complete this self assessment and consider how you can find ways to improve your friend rating.

**1 Not so good** to **5 Good friend**

I use positive and supportive language	1	2	3	4	5
I try new things to do	1	2	3	4	5
I use humour	1	2	3	4	5
I do not correct or argue	1	2	3	4	5
I am patient and flexible	1	2	3	4	5
I don't ask questions he/she can't answer	1	2	3	4	5
I am optimistic	1	2	3	4	5
I listen carefully	1	2	3	4	5
I allow my friend to talk about feelings	1	2	3	4	5
I compliment and congratulate	1	2	3	4	5
I am affectionate and caring	1	2	3	4	5
I treat my friend as an adult	1	2	3	4	5
I use common sense	1	2	3	4	5
I use familiar routines, regular visits	1	2	3	4	5
I am familiar with resources and support	1	2	3	4	5

(Bell & Troxell, 2002, *A Dignified Life*, p152).

# REFERENCES

Alzheimer Scotland, Lochaber Branch (2003) I'll Get By with a Little Help from My Friends: Information for friends of people with dementia. Alzheimer Scotland.

Bell, V. & Troxell, D. (1997) The Best Friends Approach to Alzheimer's Care. Health Professionals Press: Baltimore, USA.

Bell, V. & Troxell, D. (2001) The Best Friends Staff: Building a culture of care in Alzheimer's programs. Health Professionals Press: Baltimore, USA.

Bell, V. & Troxell, D. (2002) A Dignified Life: The best friends approach to Alzheimer's care, a guide for family carers. Health Communications: Deerfield Beach, USA.

Bezant, E. & Eaves, P. (2006) Stolen Moments. Writing to Inspire: Quinns Rocks, WA 6030.

Crisp, J. (2000) Keeping in Touch with Someone who has Alzheimer's. Ausmed Publications: Melbourne.

**NOTE:** All of the above resources can be accessed through your local Alzheimer's Australia Library.



# ABOUT ALZHEIMER'S AUSTRALIA

Alzheimer's Australia is the national peak body representing people with dementia, their families and carers. Our vision is a society committed to the prevention of dementia while valuing and supporting people living with dementia.

Alzheimer's Australia provides information, support, advocacy, education services and programs to improve the lives of people living with dementia.

Alzheimer's Australia is an advocate for people with dementia, their families and carers and encourages people with early stage dementia, their families and carers to share their voices and experiences and take part in advocacy.

For more information about our services and to find out how you can help us, visit **[fightdementia.org.au](http://fightdementia.org.au)** or call the **National Dementia Helpline 1800 100 500**

**FIGHTDEMENTIA.ORG.AU**

**NATIONAL DEMENTIA HELPLINE**

An Australian Government Initiative

**1800 100 500**