



“I’ll get by with a little help
from my **friends**”



Alzheimer Scotland
Action on Dementia

Information for friends of people with dementia

How this booklet came about

The members of the Lochaber Branch of Alzheimer Scotland were aware that many people find it difficult when a friend has dementia. They were also aware that most information available is written specifically for professionals, for family carers or for people with dementia themselves. So the process of asking people about their experiences of being a 'friend' began. Family carers were also asked what had been helpful to them and what their relatives with dementia had appreciated. This booklet is the result.

Our thanks go to

Alzheimer Scotland Lochaber Branch and Highland Carer Services and all the carers who contributed the information.



Introduction

Dementia doesn't just affect the person with the illness. It affects their families, friends, neighbours and the other people they meet.

My mum's friends don't visit anymore. She doesn't understand why and she seems really lonely.

Carer

Looking after my wife takes me all of my time. I don't get a chance to meet up with my old workmates now. It's a long day with nobody else but the two of us.

Carer

He doesn't know who I am and I don't know what to say. So I find visiting him very difficult.

Friend

People often find it difficult to stay in touch with a friend who has dementia and their family. This can mean that people with dementia and their carers can become very isolated.



What is Dementia?

I wonder what's wrong with Jim.

He doesn't seem like his old self at all.

Dementia is a condition that affects the brain. It is caused by a number of different diseases, most of which are incurable. When someone has dementia, brain cells are damaged, resulting in gradual loss of abilities. Sometimes it starts with changes in personality or difficulties in remembering things. The person may become confused about who people are, what day it is or what they should be doing.

Dementia is progressive. In the early stages the changes can be small but the person becomes gradually less able to do everyday things and needs more and more help. As the illness goes on the changes are greater and the memory problems get worse. He or she may sometimes seem upset and unreasonable.

Although there is no cure, medicines are available which can slow down the progress of the illness for some people.

More information about dementia, its causes, effects and treatments is available free of charge from Alzheimer Scotland.

It is sometimes hard having a friend with dementia

Are any of these your experiences?

- It's sad seeing the change in her and I want to remember her as she was.
- I worry about what he might say or do.
- My friend doesn't seem to know who I am or thinks I'm someone else.
- It's embarrassing for me and my friend.
- I feel guilty that my friend is like that and I'm not.
- I don't want to give anyone extra work by visiting.
- My friend talks about people who've died as if they were still alive.
- I don't know how to help.
- I'm worried about being accused of something I haven't done.
- I am worried that I will get dementia myself.
- I never know whether my friend will be having a good day or a bad day.
- It's hard to hear this person I knew well speaking nonsense.
- I don't know what to say to the family.

Why it's important to try to keep friendships going

For you:

- 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.
- Keeping up a friendship might not be as hard as you think. Just because the relationship is changing it doesn't mean it can't be worthwhile for you both.

For your friend:

- It's important for people with dementia to feel that they still matter.
- You can help your friend keep in touch with the part of the life you've shared - interests, acquaintances, experiences.
- You can help other people to understand your friend better.
- Company and activity help keep the person with dementia more able for longer.

For the family and carers:

- You can help families feel less lonely and isolated.
- Families often find friends easier to talk to than relatives.
- Friends visiting can break up a very long day.



People with dementia need opportunities to give as well as receive.

Note to carers:

You can help your friends: be honest about the illness and its effects, be open to people in the community. It helps friends be less embarrassed when taking a person with dementia out or talking about them to other friends.

What might help you...

I visit Jim once a week but he tells everyone he never sees me.

- Don't take it personally if your friend forgets your visits or says hurtful things. Remind yourself that it's the illness not the person.
- Understanding more about dementia and its effects does help. Find out more about it.
- If your friend doesn't always recognise you, remember it's how you are, not who you are, that's important.
- Short visits can be just as worthwhile as longer ones. Choose a time when you are not feeling rushed.
- Sometimes it can be easier going with somebody else.
- It's OK to talk about your life and your news, just as you always did, without feeling guilty.
- You don't have to keep conversation going all the time - just keeping company can be enough.
- Try to carry on as normal - just do the things you always did for as long as you can.

Remember, no-one gets it right every time!

How can you help your friend with dementia?

It's hard enough losing your memory without losing your friends as well.

- Don't talk about or talk over a person with dementia. It can be confusing and hurtful. Bring them in to the conversation.
- Acknowledge that your friend still has much to offer. Keep asking for their opinions.
- Help them to continue with their hobbies. A joint project may be a good idea - they can feel pride in what you have achieved together.



Help your friend to continue a hobby.

- Enjoy getting out and about and sharing news and gossip - help your friend stay part of their community.
- If your friend forgets your visit or an outing, it was still worthwhile - it was enjoyed at the time.
- Taking things like newspapers or photos can help conversation along.
- Watching television, listening to music or eating together can be companionable.
- People with dementia often remember the past best. Allow them to share old memories and past achievements.
- Remember that your friend forgets. Be patient if questions or stories are repeated.
- Speak slowly and clearly, giving your friend enough time to understand you and work out what they are going to say.
- Keep questions straightforward and don't persist if answering seems too difficult.
- Sometimes words can be very difficult for people with dementia. Use touch or gestures to show you understand.
- If your friend does something strange or embarrassing, distraction and diversion is better than 'playing along' or telling them off.
- If a visit is upsetting or has gone badly, don't be put off trying again.

How can you help the people caring for your friend?

When you're looking after someone with dementia, friends disappear like snow off a dyke.

- Visit. The length of visit isn't necessarily important. Sometimes just popping in can be best.
- Keep in touch. Even if you can't visit, a phone call is very welcome. If you've promised to visit or phone, try to keep your promise.
- The person with dementia might like to be taken out, even if it's only for a cup of tea or for a walk around the garden.
- Offer to be another pair of eyes. It's helpful for a carer to have someone with them when they are with a person with dementia on a shopping trip or outing.
- Be a good listener. Carers often need to talk but are reluctant to complain to relatives. Friends can be just the right sympathetic ear.
- Sometimes the carer yearns for some stimulating discussion, the sort of conversation they may be missing with the person with dementia.
- Don't feel you always have to say or do the 'right' thing. Often just asking if there is anything you can do can make such a difference.
- Help your friend continue to mark their carer's special days such as birthdays and anniversaries.
- Laughter is important. Many situations do have a funny side - find it and share it.

Does your friend live alone?

It is particularly hard to be a neighbour of someone with dementia who lives alone. You see and hear things which might be concerning, but can feel unsure of who to tell, or talk to, or what to do for the best.

- Find out if there is a relative visiting. Often, they are unaware of all of the difficulties and are relieved to know that someone is taking an interest.
- If there is a nurse or care worker visiting, they are usually happy to listen to your concerns, although they will not be able to give you any information about the person with dementia.
- Don't feel responsible for solving problems.
- **Contact Alzheimer Scotland for information, advice and support.**



Is your friend living in a care home?

I find it really hard visiting Jessie in there.

- Regular, short visits are often better than long, rare ones.
- Don't make assumptions about what the staff will allow you to do. Ask if you can take your friend out, help with their care or visit their room.
- Take in local news and gossip - it keeps your friend part of the community. Remember to take the good news and bad.
- Perhaps a recording of favourite music can be listened to together, maybe a musical instrument they used to play.
- Think about what your friend did long ago and take in things to remind them. Perhaps a browse through some photographs.
- Take familiar playing cards, dominoes, jigsaw, or crosswords. Concentration may be a problem so activities may have to last for only a few minutes.
- Save up your postcards or take some travel brochures. Share holiday memories and dreams.
- If conversation is difficult, take newspapers or magazines to read - you can read snippets out from time to time.
- Well behaved children and dogs can give great pleasure.

- A book by the bed to record who has visited and what they did or brought in is helpful.
- Offer to go with other friends who are shy of going alone.
- Other residents and visitors will also value your visits.
- There doesn't have to be constant conversation. You can both enjoy just sitting quietly together watching the world go by.



Physical contact can often be appreciated - doing your friend's nails or hair, or maybe just sitting holding hands or tapping out the time to some music.

Has your friend died?

- If you can, attend the funeral. It is a great comfort to carers. Even if you have lost touch your presence at the funeral will be appreciated.
- Taking some photographs of you and your friend with you to the funeral or when you visit the relatives later can bring back happy memories.
- There is a huge gap for the carer when the person with dementia dies. That can be really hard. Visiting or phoning to share memories of your friend will help fill this gap.
- Caring for someone will often have been very socially isolating. An invitation out can help a carer become part of the world again.



Send a card or letter. They can be a great comfort to carers at the time and later.

Where to get advice and information

If you would like to talk to someone in confidence about any anxieties relating to your memory, someone else's, or any queries or concerns about dementia, or to get a free information pack contact:



Alzheimer Scotland

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About Alzheimer Scotland

We:

- run local specialist dementia services across Scotland, including day care, home support, and counselling
- provide an information service, Dementia Helpline: 0808 808 3000, and website: www.alzscot.org
- provide carer education and support
- campaign for better services and raise public awareness through our branch network and other activities
- rely on fundraised income to support our work.

24 hour freephone Dementia Helpline 0808 808 3000



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with dementia, their carers and
their friends

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