

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

Information for friends of people with dementia



Making sure nobody faces dementia alone.

Alzheimer Scotland – Action on Dementia

Alzheimer Scotland is Scotland's leading specialist dementia charity and works to improve the lives of everyone affected by dementia. We provide information, support and a network of services and support groups from more than 60 sites around Scotland. We also campaign to improve public policies and services for people with dementia and their partners and families.

Can you help us?

We need your support to help us to provide our networks of Dementia Advisors and Dementia Nurse Consultants across Scotland, our Dementia Helpline, the Alzheimer Scotland Dementia Research Centre, our Reminiscence Networks, and to campaign for the rights of people with dementia, their partners and families.

You can support our work by:

- donating regularly with a monthly gift, enabling us to plan ahead with confidence
- taking part in our fun events held throughout the year in Scotland – or hold your own event – see our Fundraising Toolkit at <http://my.alzscot.org/>
- becoming a member and adding strength to our campaigning voice
- leaving us a legacy or setting up a tribute fund
- becoming a Dementia Friend
www.dementiafriendsscotland.org

Introduction

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

Most information about dementia is written specifically for professionals, family carers or people with dementia themselves but many people find it hard to know what to do or how to help when a **friend** has a diagnosis. They often find it difficult to stay in touch with a friend who has dementia and their partner, spouse and family. This can mean that people with dementia and their carers can become very isolated.

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

Daughter

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.

Husband

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

Friend

This booklet recognises some of the challenges of maintaining friendships with people living with dementia and suggests ways that friends can stay involved and supportive.



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.

Every person with dementia is different. How their illness affects them depends on which areas of their brain are most damaged.

One of the most common symptoms of dementia is memory loss. Everyone forgets things sometimes and most people's memory gets worse as they get older. But when someone has dementia, they may forget the names of friends, not just of strangers. They may repeat the same question or information again and again and not know they are doing it.

People with dementia may lose their sense of time, losing awareness of which day it is or of the time of day. They may forget appointments or arrangements made to meet up with friends. They may lose track of where they are, and get lost even in a familiar place.

Dementia can also cause personality and behaviour changes. Someone who was active and energetic may become listless, someone pleasant and well-mannered may become rude and aggressive. These changes can be particularly distressing to relatives and friends as they lose the person they knew.

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.

More information about dementia is available free of charge from Alzheimer Scotland's 24 hour freephone Dementia Helpline on 0808 808 3000 or by visiting www.alzscot.org

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.
- I don't know what to say to the family.
- It's hard to hear this person I knew well speaking nonsense.

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 spouses, partners and the family:

- 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.

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. And don't be afraid to ask for help.



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 visiting 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 or interests. A joint project may be a good idea – they can feel pride in what you have achieved together.
- Ask your friend what sort of support he or she would like from you. It might be a specific role like driving them to the shops or going to the pictures or for a regular walk or maybe just dropping by for a cuppa and a chat.



- 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 family 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 friend or 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 24 hour freephone Dementia Helpline 0808 808 3000; www.alzscot.org



Does your friend live 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, jigsaws, 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, but check with the home first.
- 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.

Has your friend died?

- If you can, attend the funeral; it can be 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 partner or family carer become part of the world again.



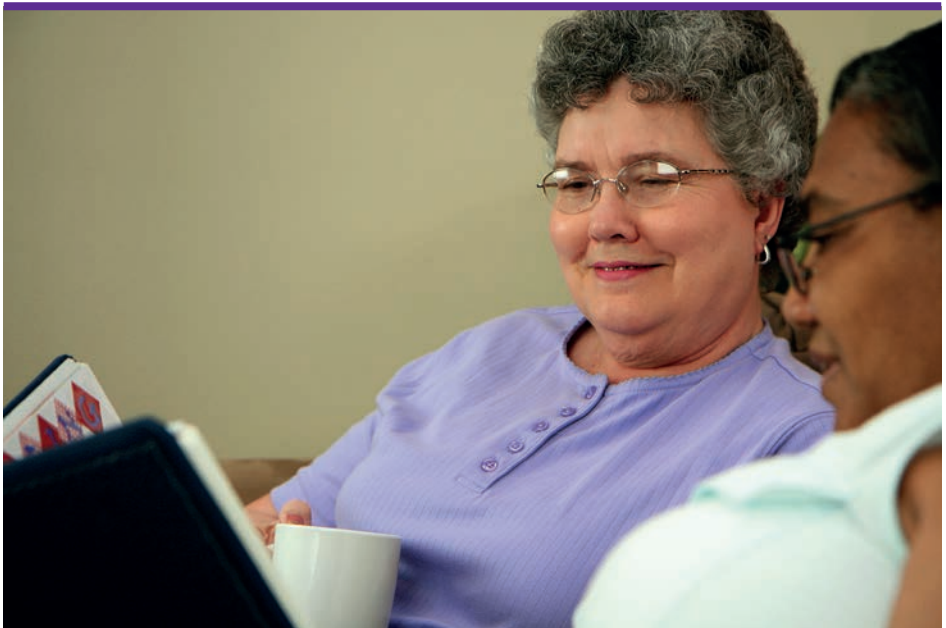
Where to get support and information

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
22 Drumsheugh Gardens, Edinburgh EH3 7RN
0131 243 1453; info@alzscot.org

www.alzscot.org





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