

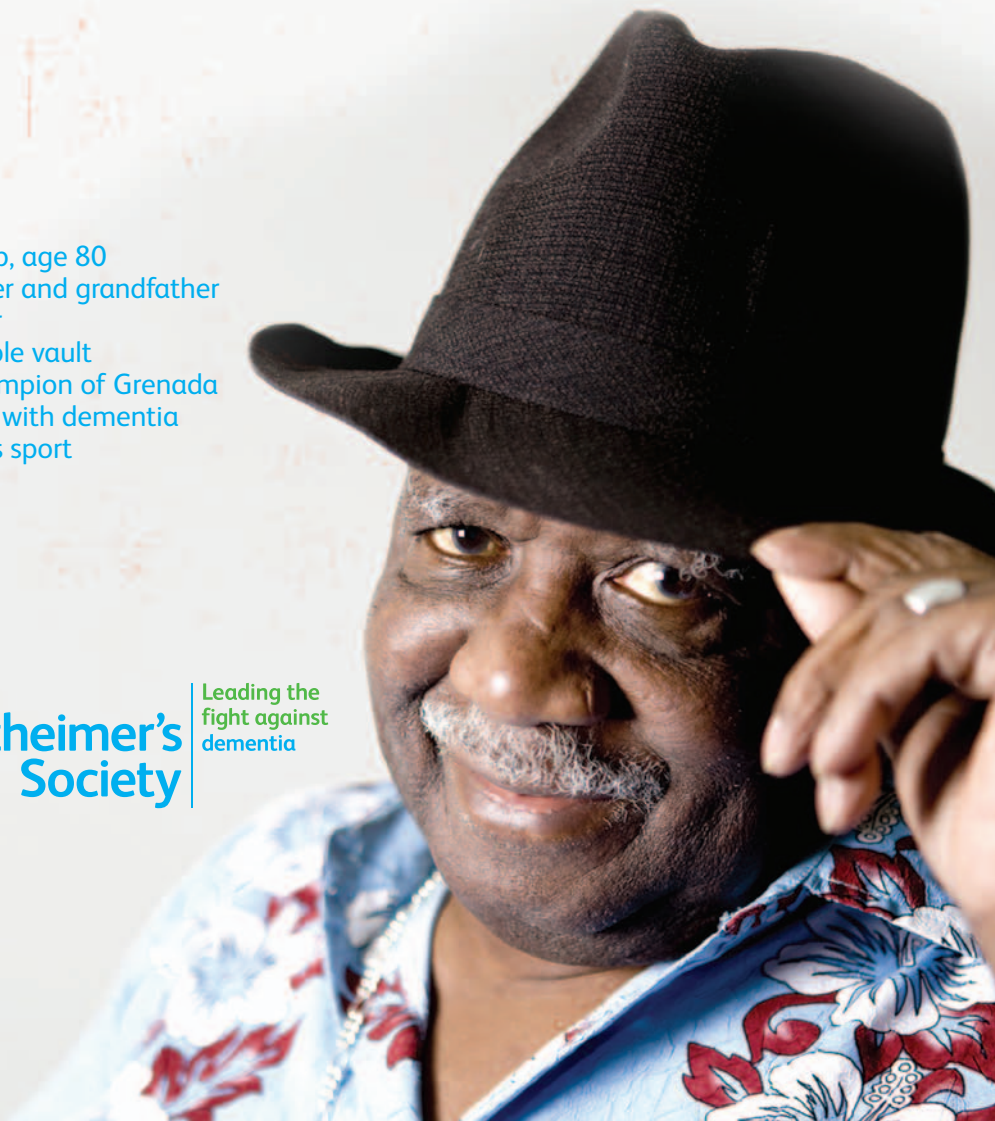
REMEMBER THE PERSON

How to be a friend to someone with dementia

Phillip, age 80
Father and grandfather
Tailor
Ex-pole vault
champion of Grenada
Lives with dementia
Loves sport

Alzheimer's
Society

Leading the
fight against
dementia



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What is dementia?

Dementia is a set of symptoms caused by some diseases or conditions that affect the brain. These symptoms include memory loss, mood changes and communication problems.

There are many different causes of dementia, including Alzheimer's disease and stroke. Different people are affected in different ways, depending on the type of dementia, and on the individual's personality, lifestyle and state of health.

Dementia is progressive. This means that the symptoms get worse over time. In the later stages, someone with dementia will find it difficult managing even simple tasks, and will need more and more support from others.

There is no cure for dementia yet, but there are some treatments that can delay the progression of some forms of dementia, and there is ongoing research into finding a cure.

Meanwhile, many symptoms that can accompany dementia such as anxiety can be treated, and we are constantly learning new ways to make life for people with dementia more manageable and enjoyable.

Dementia is a challenge, but life with dementia can still be full of joy and laughter. People with dementia are still people, after all.

What's it like to live with dementia?

John, living with dementia

'When I was diagnosed with Alzheimer's obviously I wasn't happy, but I wasn't devastated, because I'd seen my mother and aunt through it.

My mother never suffered pain or panic – she lived in a happy world of her own. The only sufferers really were her close family, seeing her like that. There are things I'm sad about. I don't dream any more. Or when you're half asleep and can conjure up people's faces, or being in a beautiful place with someone you love... for me, the memory bank's been erased. Computer says no.

On a daily basis, the most frustrating thing is forgetting things. People say "Write it down" – but then you forget to look at the piece of paper! It's a huge problem for me, and it makes me want to kick myself!

Because I run a couple of committees, I had to say, "Look, I do have Alzheimer's. Do you feel confident in me running these meetings?" And they all stood up and applauded. That was one of the good days. I still do it – out of enjoyment, and I hope it keeps me alert.

I'm very happy at the moment.'



John, living with dementia

Ten ways you can help a family living with dementia

1 Treat the person with respect and dignity

When someone you know has dementia, it's easy to focus on the dementia instead of the individual. But it's important to remember that someone with dementia is still a unique and valuable person, just like anyone else.

When someone finds that their mental abilities are declining they often feel very vulnerable, so it is very important to help them feel confident and valued, and to encourage them to achieve small things for themselves.

Above all, try to be positive. Let the person know that they are important to you.

'It's nice to be treated like everybody else and not being separated – and being as involved in life as you always were. I don't want to be different.'

John, living with dementia

2 Be a good listener

When someone has dementia, or is supporting a loved one with dementia, it can really help them to talk things through. You can help by making time to listen – even if this is just with a short weekly phone call to see how they are.

Ask thoughtful questions, and give the person time to explore their feelings. Listen carefully, rather than jumping in with suggestions: you may find that the support they need is not what you had expected. It can be tempting to offer practical solutions, but often people just need a chance to say how they feel. Try to be supportive and accepting, and not to judge.

If you are listening to someone with dementia, think about how things appear from their perspective. If they are anxious about something, rather than telling them that their fears are irrational, try to imagine how that must feel for them.

'You need to let the person think. The answers don't come as quickly as they used to.'

Lesley, living with dementia

3 Be a good communicator

People with dementia can become confused at times, so it's important to communicate clearly with them. Try to speak calmly, waiting for signs that the person has understood what you have said.

Communicating isn't just about talking. Non-verbal communication is very important too, especially for someone who is losing their language skills. So, pay attention to your body language. Make sure you look the person in the eye, talk to them at eye level, and use physical contact, such as a pat on the hand, to offer reassurance.

Your tone of voice is important too. Even if someone doesn't understand the words you are using, they may sense if you are irritated, stressed or anxious. If you can convey a sense of warmth and reassurance, they will be more relaxed and content.

'Because I forget quite quickly what people have said, I tend to get off track. I like it if the person brings me back to the main point of the conversation. But the most important thing is to look me in the eye.'

John

4 Remember that the little things can mean a lot

The idea of supporting someone whose life is affected by dementia can feel overwhelming. Some people worry about making a commitment that they can't keep, or getting involved in a situation that they can't handle. Some find it so difficult that they lose touch completely with their friends and family.

But it doesn't need to be like that. Doing something that seems very small can make a big difference to someone living with dementia. Dropping in for a cup of tea, or helping them organise their photo album, can make them feel that someone cares.



Lesley, living with dementia

5 Stay in touch

People with dementia and their loved ones can easily become isolated as dementia progresses. Old friends can lose touch over time, but when someone's life is affected by dementia this can happen simply because people don't know how to behave with them any more.

If it's not practical to visit the person, why not give them a ring, or write a letter or email? If you're really pushed for time, drop them a postcard or send a quick text message just to let them know you're thinking about them.

Hearing from someone briefly and frequently is better than receiving a long letter twice a year, so don't put it off and keep in touch.

'People do tend to keep in touch with me, and it's highly appreciated. They'll keep phoning even though I forget to return the calls. They understand, because they know my position.'

John

6 Offer practical help

Two thirds of people with dementia live at home. Even those who are independent may welcome help with some tasks. Carers may be glad of help too – not least because they're often short of time.

An easy way to help out is to offer practical support. Help the person tackle something on the 'to do list' – cut the grass, put the rubbish out, cook a meal or run an errand.

For some people remaining independent is important and it can give them a sense of great pride. So it's important to find a balance between being insistent and knowing when to step back. If someone is fiercely independent, try to think of a two-person job that they might struggle with on their own.

'I wanted to make a lawn at the front, but it would need digging and planting grass, and that's too much for me now. If someone wanted to help me with that, I wouldn't mind at all'.

Phillip, living with dementia

7 Organise a treat

Almost everyone enjoys a special treat now and again. It can be something to look forward to and a welcome break from everyday routine.

If you are planning a treat for the person with dementia, think about what they liked to do before the illness, and whether you need to adapt an activity to their current situation. You could go for a drink in their local, have a picnic in the park, or take a trip to the seaside. Or you may prefer to spend time indoors, watching an old film or the football.

If you'd like to arrange a treat for a carer of someone with dementia, ask whether they would like the person to come too. If they would prefer to join you alone, help them think through who will look after their loved one so they can relax and enjoy planning the day with you.

'It would be nice to do something different. I'm easily pleased! But I'd want to get out of the house. I'd like to go to the shops or a dance club – somewhere you're meeting people and doing stuff.'

Lesley

8 Help different family members in different ways

It is not only the person with dementia who is affected by this condition – it also has an impact on anyone who is close to them. Some family members may dedicate a lot of time to caring responsibilities, and have little time to do practical things like tidying the house, let alone reading a book or having a soak in the bath. Filling in as a carer from time to time will offer welcome relief.

Others, including children and grandchildren, may be affected emotionally. They may be upset about the changes in their loved one, frustrated by disruptions to their home life, distressed that they cannot be more involved, or concerned that they may develop dementia themselves. Offer them a chance to talk things through and express what they are feeling.

9 Find out more about dementia

The more you know about dementia, the more comfortable you will feel spending time with the person with dementia or their loved ones. Dementia can make people behave differently, but once you understand that these changes are part of the illness, you will find it much easier to take them in your stride.

If you feel you don't know enough about dementia, it's easy to find out more. Our website has lots of information about dementia and the ways it can affect people and their loved ones. Alternatively you can phone our helpline on 0845 300 0336.

'When I've told people I've got dementia, you can see them looking as if I might turn into some strange creature. But it's not that I'm going to hurt people or anything – just that I can't remember things.'

Lesley

10 Direct people to Alzheimer's Society for more help and support

We run many different types of services that can help a family living with dementia from helplines to support groups, and from befriending services to social activities.

If you know someone whose life is touched by dementia, ask them if they have contacted us yet. If they haven't, give them our details, or find out about our services in your area and pass on the information. We support 30,000 people each week in England, Wales and Northern Ireland, so we are well equipped to make a difference.

'Alzheimer's Society is important. You get to know what dementia is all about, and then you can pass that on to other people. I'd recommend it to anybody who wants to know about dementia.'

Phillip

How you can help us

Each year, 100,000 people in the UK develop dementia. Most of us know someone whose life has been touched by it in some way. But even if you don't, there is plenty you can do to help Alzheimer's Society improve the quality of life of people affected by dementia.

Donate – We need to raise money to help people live well with dementia today, and for research to find a cure for tomorrow. Make a one-off donation or set up a regular payment through Direct Debit. You can also leave a legacy to us, or ask for donations rather than gifts for celebrations, such as weddings.

Fundraise – Do a sponsored walk, run, cycle, trek or parachute jump. Get involved in national fundraising events such as our annual Memory Walk, take part in regional events, or set up your own event, such as a raffle, a car boot sale or a cake bake. Our corporate team also helps companies find ways to offer support, from fundraising to setting up payroll giving.

Volunteer – Volunteering is a great way to help people with dementia while developing skills and having new experiences. Roles range from running support groups and acting as a Dementia Adviser to befriending and administration.

Campaign – The government currently provides eight times less funding for dementia research than for cancer research, even though dementia costs the UK more than stroke and heart disease combined. By signing up to our Campaigners' Network you can help us make dementia a higher priority for the people with the power to decide.

Get involved and help us make a difference to people's lives. Visit alzheimers.org.uk to find out how.



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About John, Lesley and Phillip

John, 68

John is a retired entertainer who toured the world with his drag act, performing for audiences including royalty and film stars.



‘The worst day of my life was the day I found out I had dementia and had to leave the profession that had been the passion of my life,’ he says. ‘The music would start, and although I’d sung the song a thousand times before, I’d lose the words.’

Never one to stand still, since retirement John has found a new lease of life, playing an active role in the running of the estate where he lives. And once a week he runs a pensioners’ afternoon, with bingo, karaoke and dancing.

‘So I’ve got a microphone in my hand again,’ he smiles. ‘I look forward to it every single Friday!’

Lesley, 65

Lesley has worked with children and young people all her life – initially as a nursery assistant, and later working with social services to support families. ‘It was what I loved doing more than anything,’ she says.



Lesley was very sad to retire after being diagnosed with Alzheimer’s disease at just 61 years old, but continued to use her skills through volunteering. Today she runs a group for young people with learning disabilities: ‘It’s my way of giving back what people have given to me,’ she explains. ‘And they’re so loving, it makes me feel that I’m normal again.’

Lesley loves dancing, shopping and fashion, and has a sharp eye for a bargain in the charity shops. ‘I sneak in and look around, and nobody knows! I get a great kick out of that!’ she laughs. ‘I think I’m very lucky because I’ve got some lovely friends, and my daughter’s brilliant,’ she adds, ‘I enjoy life.’

Phillip, 80

Phillip is a retired tailor and a lifelong sports fan. He was born in Grenada in the West Indies, and was the pole vault champion for the country.



Phillip lives alone, and is still very independent, but he does feel limited by his dementia. 'The most difficult thing is I can't find my way, especially at night-time,' he explains. 'Sometimes it makes me frustrated, but I have to take it in my stride,' he says. 'I don't get agitated.'

Today Phillip continues to watch sport every day, and his home sees a constant stream of visitors who join him to watch a match. 'I have an open door to people I know,' he says. 'They come in, sit down, we might have a drink or two. It's very rare that I don't have somebody with me.'

About Alzheimer's Society

Alzheimer's Society is the UK's leading care and research charity for people with dementia and those who care for them.

There are 750,000 people with dementia in the UK with numbers set to rise to 1 million by 2025.

The Society fights for a better world for people with all types of dementia in a wide variety of ways. Through our network of over 2,000 services, we touch the lives of over 30,000 people every week, providing practical services and support for people with dementia and their carers. Every year, more than 1 million people make use of the information we provide.

Through campaigning and lobbying activities we strive to influence government policies and raise awareness of the challenges faced by people with dementia and the people who care for them. Through our research programme we work to improve the knowledge we have about dementia and its treatment and pursue the ultimate goal of finding a cure.

Alzheimer's Society Dementia Helpline
England and Wales: 0845 300 0336
Northern Ireland: 028 9066 4100

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