

**If you kiss someone,
would they get
dementia?**



Ask Us Anything

**How to start a conversation with
someone living with dementia**

DAW19WB



We need to talk about dementia

Every three minutes someone in the UK develops dementia. It could be your mum, your brother, your neighbour or your best friend.

But despite almost all of us knowing someone affected, two-thirds of people living with dementia report feeling isolated and lonely.

Alzheimer's Society is determined to change this and create a dementia-friendly world. A world where people with dementia are included and supported to live the lives they want, and their rights are upheld. There are over 420 communities becoming dementia-friendly in England and Wales already. But we need more people to show their support.

You can join us. It can be as simple as getting in touch with the people affected by dementia that you know and having a chat.

This booklet is about how starting a conversation can make a difference to someone's day-to-day life, and make someone with dementia feel included in family, friendships and their wider community.

As well as practical advice about talking to someone with dementia, you'll find ideas on how you can take bigger actions and unite with us as a volunteer, fundraiser or campaigner to create lasting change.

Every time we talk about dementia we get a step closer to creating a more, supportive society. The kind of society we can all be proud to be part of.



Don't just look at the dementia. Look at me. I'm still here. Ok, so I get in a muddle, I get lost, and there are all sorts of things I can't do anymore. And that does make me frustrated. But I'm still Joy.

Joy, living with dementia



Getting to grips with dementia

Dementia is caused by diseases of the brain, it isn't just about memory loss. Different types of dementia can affect people in lots of other ways, from feeling confused and having difficulty concentrating, to behaving differently.

Communication skills might change, for example forgetting words or having problems following a conversation. Coordination can be affected too, so it might become difficult for someone with dementia to use a knife and fork.

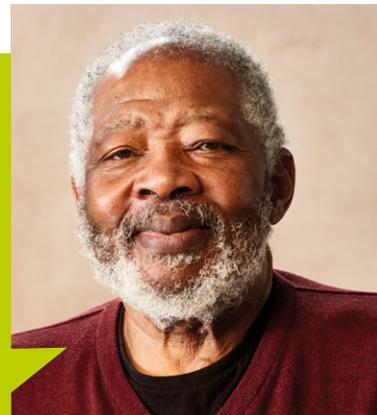
Lots of everyday tasks can also become more difficult, such as getting dressed or having a shower.

Changes in vision and perception are common in people with dementia too. Distance and space can be misjudged and everyday objects might not be recognised.

But someone with dementia is still the same person. They're still the mum, dad, brother, sister, friend or neighbour you've always known.

'It's very difficult to explain what dementia is. When I'm talking to someone, I have to try my best to make sure people don't just think I'm not interested because I'm acting differently. I might not be able to give the answers I used to, but I've got a lot to give and you've got to keep on trying.'

Kenrick, living with dementia



It's time to start talking

'I love it when people ask me questions because I feel included. It gives me an opportunity to show that people with dementia exist, that we can still contribute to what's going on around us and that life goes on. It makes me feel good. It makes me feel like me again.'

John, living with dementia



We know it can be hard to find the right words to say when someone you know is diagnosed with dementia. And sometimes it feels easier to say nothing at all. But staying connected is so important, for everyone.

By spending time with a person with dementia, you'll help them feel included and part of the community. You may be surprised and you'll probably learn a lot.

Keep it simple. Invite a friend round for coffee, go out for a walk, or watch a show together if that feels right.

It's ok to ask someone how they feel – it's good to talk about dementia.

Don't feel embarrassed or awkward talking about dementia. We need to have these open conversations to help create a dementia-friendly society. Talking leads to change.

Always respect a person with dementia's wishes. If they're not ready to talk about dementia yet don't push them. You can try again at another time. It can help just knowing you are happy to talk to them when they're ready.

What if I say the wrong thing?

It really doesn't matter. Even if you feel a bit awkward to start with, chances are you'll have made someone's day simply by having a chat.

Here are some useful tips to make things easier when you're talking to someone with dementia.

Give the person with dementia your full attention and try to speak to them face-to-face. Be patient and give them time to respond.

Speak clearly and make sure your body language is open and relaxed. Speak in a friendly and chatty way.

Try to laugh with the person about any mistakes or misunderstandings.

When asking questions it can help to give a short list of options. Or keep to questions that have a yes or no answer.

Have a topic of conversation in mind. Is there something the person with dementia is particularly interested in or that makes them laugh?

What not to say

There's no right or wrong thing to say. Everyone's different. But there are some things that can be frustrating for a person with dementia to hear.

'Remember when...?'

This can be a reminder of lost memories that might be painful or frustrating. Instead, try leading with your own memory. That way the person has time to think without feeling embarrassed. Or just enjoy the present moment.

'Do you need some help with that, love?'

Words like 'love', 'honey' and 'dear' can be patronising for people living with dementia. Remember the person behind the dementia and use their name.

'I've just told you that'

Try not to get frustrated and be as patient as possible. Reminding someone with dementia of what they've forgotten won't help.

'Do you recognise me?'

This could make a person with dementia feel bad if they don't remember you. It might help to say your name in a casual way when you first greet someone.

Making a connection in the later stages of dementia

It might become difficult to have a conversation with someone in the later stages of dementia. But that doesn't mean you should stop seeing them.

Seeing friends and loved ones can bring someone feelings of happiness and comfort. The person may not remember that you've been but the emotional connection often stays after the visit.

When talking feels tough, there are other things you can do to make communicating easier.

- Non-verbal communication can really help. Think about your facial expression and body language, as well as using hand gestures. Smile when it feels right.
- Singing and making music can be a great way for people with dementia to express themselves and feel connected to others.
- Holding hands with someone lets them know you're there and can give them reassurance.
- Try doing an activity the person enjoys together. Creating a memory book is a great way for family to connect with the person and it can help communication.

'It's so good to see my husband remembering the words to songs. He doesn't speak much now yet he can sing every word.'

A carer of someone living with dementia

Start a conversation on social media

Don't underestimate the power of your computer or smartphone.

Social media plays a massive part in inspiring others, so follow us on Twitter, Facebook and Instagram to show friends and family you're uniting with us against dementia.

Every comment, share and like we get helps us reach more people.

And the more people we reach, the closer we are to creating a dementia-friendly society.

Join in the conversation on Twitter
@alzheimerssoc

Find us on Facebook
facebook.com/alzheimerssocietyuk

Follow us on Instagram
@alzheimerssoc

To join our conversation use
the hashtag
#AskUsAnything



Unite with us against dementia

Starting a conversation is just the beginning. Help us beat dementia for good.

Learn what it's like to live with dementia and take action

Become a Dementia Friend and join 2.5 million people who already are. You'll learn more about what dementia is and how to support people affected in your community. Whether you're an individual, group or business, you can get involved. When enough people join us and take actions, however small, we will change the lives of people with dementia.

Volunteer with us and make a real difference

We have lots of volunteering opportunities, from taking part in research, to joining our Side by Side service and helping someone with dementia to continue to do the things they love.

Fundraise to help defeat dementia

We fund research into the cause, cure, care and prevention of dementia. Every penny helps, so from holding your very own Cupcake Day to running a marathon, do your thing and help us beat dementia.

Campaign to improve care

Sign up and add your voice to our campaigns. Over the last year our campaigners have influenced hundreds of decision-makers to improve the lives of people affected by dementia.



Are you affected by dementia?

Alzheimer's Society is here to help. We offer support for everyone affected by dementia, including family members, friends and carers.

As the UK's leading dementia charity we provide expert information, training, and support services to those who need our help. And we're creating a more dementia-friendly society so people with the condition can live without fear and prejudice.

If you need support, advice and information call our Dementia Helpline on **0300 222 11 22**.

Dementia Talking Point is our online community for anyone affected by dementia. Talk to others and share experiences 24 hours a day, seven days a week. **alzheimers.org.uk/talkingpoint**

You can find dementia services and support groups in your area through our Dementia Directory. Find out what's available near you. **alzheimers.org.uk/getsupport**

Our website has lots of useful information on dementia, including accessible resources, factsheets and legal advice. **alzheimers.org.uk**





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Alzheimer's Society operates in England, Wales, Isle of Man and Northern Ireland. Registered charity in England and Wales (296645) and Isle of Man (1128)

Alzheimer's Society is the UK's leading dementia charity. We provide information and support, improve care, fund research, and create lasting change for people affected by dementia.

Find out more at
alzheimers.org.uk

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