

# Staying connected

A guide to dementia-friendly  
conversations



**A guide for carers,  
relatives and friends**

# Welcome



# Contents

|  | <b>Page</b> |
|--|-------------|
| Foreword   | <b>4</b>    |
| About this book  | <b>6</b>    |
| How someone living with dementia experiences the world | <b>8</b>    |
| Tips for conversations                                 | <b>14</b>   |
| Uncomfortable conversations                            | <b>26</b>   |
| Staying connected without words                        | <b>30</b>   |
| Additional support and advice                          | <b>39</b>   |

# Foreword from Jo Crossland

*“Consider the dementia, but always remember the person.”*



Dementia affects how the brain works, which can sometimes change the way a person is able to communicate. This is something I like to remind people who are having difficulty communicating with a loved one with dementia. An individual's personality doesn't usually change dramatically, what does change more commonly is the ability to cope with the increasingly unsure, and often overwhelming, world around them.

This is something I like to remind people who are having difficulty communicating with a loved one with dementia. An individual's

Messages in the brain may take longer to reach the right place, which can make conversations more challenging. This isn't intentional — it's just the result of the brain being affected by the condition.

It is important to keep hold of the fact that people living with dementia are generally doing their best to make sense of a world that may no longer feel familiar, with a brain that works differently than it used to.

You can read more about how dementia impacts the brain, and how this can affect how you communicate and connect with your loved one, on page 9.



This guide has been developed to support you to understand some of the ways dementia can impact a person's ability to communicate, to provide advice for making day-to-day communication less stressful, and to address some of the myths that persist around dementia.

It might seem overwhelming at first, but many of the tips in this guide are easy to use. They are designed to support you and your loved one, whether you are visiting, caring for them at home, or planning for the future after a diagnosis.

**Jo Crossland, Head of Dementia and Lifestyle at Care UK**

**“Messages in the brain may take longer to reach the right place, which can make conversations more challenging.”**

# About this booklet by Alison Butler

Receiving a diagnosis of dementia is a life changing event for a person, and for their family, even if there may be a sense of relief after many GP visits in search of answers.



Whatever your initial reaction, it will often raise questions about how life will change — both for the person with dementia and for their family.

We hope it offers you some comfort to hear that it is possible for someone with dementia to live a fulfilling life. Maintaining communication and connection with loved ones is an important part of this.

However, from our conversations with families — and the results of a national survey\* commissioned by Care UK, which explored some of the challenges of communicating with a relative with dementia — we know that many families feel they don't have enough support. In fact, the survey showed that two-thirds of people who have a relative living with dementia have never received guidance or training on how to interact with them.

For families and friends, remaining connected can feel overwhelming as a person's dementia, including



cognitive impairment, progresses. Nearly all survey respondents (93%) felt communication barriers prevented meaningful interaction with their relatives. More than a quarter said difficulties communicating with their relative held them back from visiting.

We hope these practical tips and guiding principles will help you to communicate and remain connected with your loved one.

**Alison Butler, Specialist Dementia Lead at Care UK**

**“93% of people feel communicating barriers can prevent meaningful interaction with their relatives.”**

# How someone living with dementia experiences the world



Dementia is a broad term used to describe a condition where there is an ongoing and generally irreversible decline of the brain and its abilities. When dementia progresses, it can affect the brain in a way that impacts the ability to communicate.

Take some time to try and imagine yourself in the shoes of the person living with dementia. This can help you to understand why communication becomes difficult and how making a few changes can be of huge benefit.

### **Dementia and the brain**

The areas of the brain affected by dementia — and the difficulties experienced as a result — depend on the type of dementia and other factors, like the person's previous skills and abilities.





Changes to the brain can interrupt the chemical messages that help us think, speak, and understand. As these messages take longer to reach their destination, communication can naturally become more challenging. These changes can cause difficulties for those living with dementia, including:

- increasing memory loss
- being unable to recall the names of family members
- difficulty with concentration or co-ordination
- becoming very angry or emotional for no apparent reason
- not being able to regulate actions and reactions, including the content of speech

Although it can be frustrating for families and friends to experience these changes, for instance when a loved one

repeats questions despite receiving answers, it's important to remember that they are not doing it on purpose — and it can be just as frustrating for them.

### **Living in a different time**

People with more advanced dementia can experience what is called an 'altered reality'. Your loved one may experience episodes where their brain makes sense of the world based on the reality of their younger self.

Altered realities can cause the world to appear very different for people living with dementia. This can also happen because of perceptual difficulties or hallucinations.

Sometimes, a person may not recognise their adult children, or they may ask for a relative who has passed away. These moments can be painful, but it is important to understand that this is due to changes occurring in the brain.

Trying to bring the person back to the present day is rarely helpful and can cause more distress.

People living with dementia can often recognise and enjoy spending time with those who are significant to them, even if they cannot correctly identify them by name.

### **Learning to live for the moment**

You don't need to talk about what you did yesterday to laugh together today. You just need to find out where your loved one is, in their time, to connect once again.





## Tips for being in the moment with a loved one living with dementia

### Reassure rather than reason

Instead of trying to bring your loved one back to the present, focus on reassurance. They are doing their best to cope with a brain that is affected by dementia, so avoid challenging or reasoning with their actions or reactions. Listen carefully and try to understand where they are in this moment. Talk about the period of time they are experiencing right now, and offer comfort rather than correction.



### Ask simple, engaging questions

Rather than asking "Do you remember?", which can feel stressful, focus on topics your loved one enjoys talking about. For instance, if they mention their brother and how he fell off his bike, chat about their childhood. If they mention their wife on their wedding day, ask them more about that special moment. This approach encourages connection without causing distress.





### Try listening more than talking

Close listening can help you to get a real sense of how they are experiencing the world at this moment in time. You might find words that you didn't understand at first will make more sense now. When you do speak, try talking slowly and using shorter sentences.



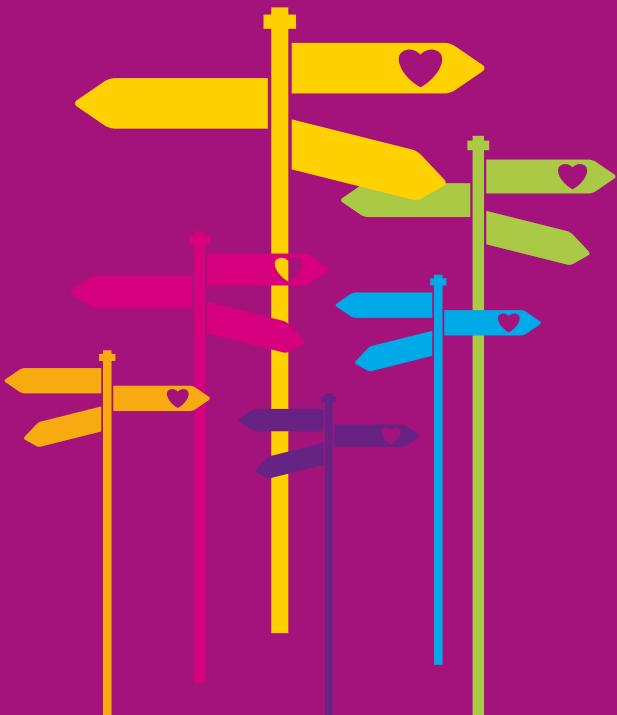
### Be flexible and avoid rigid plans

If your loved one is having a good day, take full advantage and suggest a trip out or a walk in the garden. If they aren't, don't take it personally. Allow them to set the pace and agenda for the day.



**“54% of respondents to our survey said they were most worried about their loved one becoming disoriented and confused.”**

# Tips for conversations



The idea of striking up a conversation with a loved one living with dementia can feel overwhelming. For some people, this can even hold them back from visiting at all.

In fact, 26% of respondents to our survey said difficulties communicating with their loved one kept them from visiting more often. But it's often easier than you think to communicate and connect.



Take a look through our practical pointers for tips on how to adapt your communication style to meet the needs of someone living with dementia.

**“26% of respondents to our survey said difficulties communicating with their loved one kept them from visiting more often.”**

# Practical pointers for...

## Starting a conversation

- Create a memory box that focuses on your loved one's home, work or family to prompt conversations. It can be something as simple as a shoebox covered with images that are meaningful to your loved one.
- Use pictures and trinkets from when they were younger. For example, badges and medals; tickets or programmes; keepsakes from holidays or hobbies.





- Find some old TV adverts online, old match programmes or history books of their local area to make conversation about their younger years.
- Create a playlist of songs from significant moments in your loved one's life. For example, songs from childhood, or even those that were sung with the persons own children. Just be mindful of what type of emotion these songs might evoke.
- Bring in a favourite baked treat or even try some baking together if that's something they loved to do in their younger years.
- Turn off any background noise. Blaring radios, loud televisions and even a distracting hum can be confusing for a person living with dementia.



## Talking and listening

- Use clear and straightforward language – but avoid being patronising.
- Avoid irony and sarcasm. Jokes like “Lovely weather, isn’t it?” when it’s raining can be confusing. Speak literally and simply to make communication easier.
- Try not to lie to a person with dementia and avoid talking about them as if they aren’t there, even if your intentions are kind. Honesty helps maintain trust and dignity.
- If you don’t understand something they have said, don’t give up. Make it clear that you are listening and



that they have your full attention. It can be hard but try to be patient and look for a meaning.

- Avoid talking across people, which can happen when several people are visiting at once.
- Be patient with repetition. Your loved one may repeat stories, questions, or concerns many times. Although this can be frustrating, it is important to remember that this isn't intentional — this is due



to changes occurring in the brain affecting short term memory stores. Try to respond as if you are hearing it for the first time. Over time, your familiarity with the topic may even help you anticipate helpful responses.

- Express one idea at a time. Tell stories in bite-sized pieces, using short sentences and speaking slowly if needed.
- Give the person plenty of time to get their message across, judging from their reactions if they would like you to help them make their point. If your loved one seems comfortable talking, then let them carry on for as long as they want, but, if they seem distressed, it might be a good idea to lend a hand.

## Asking questions

- Use closed questions and keep them simple and straightforward. Rather than asking "What would you like for breakfast?" ask "Would you prefer some toast or some porridge this morning?" If you can, show the options too. Having a visual cue will make choosing even easier.
- Offer just one or two choices. Giving too many — for example, asking if a person would like tea, coffee, juice or water — can cause them to feel overwhelmed.
- Encourage people living with dementia to retain their independence. Ask "Would you like a cup of tea?" rather than saying "Let's have a cup of tea".



## Getting out in the fresh air

- Outdoor and nature-based experiences form some of our strongest emotional memories. Older people will have spent a large part of their childhood and early lives outdoors, whether through play or as part of travelling to school and work.
- By providing experiences that are outdoors or nature-based, there are many opportunities for reminiscence. Exploring this part of a person's life history can provide new information about their likes and dislikes, and, in turn, promote wellbeing by finding meaningful experiences.



## Making the most of a visit

- Think about the timing of your visit. The middle of the day can often be a good time as many people with dementia can find the evenings more difficult. If you are visiting a loved one in a care home, you could even call ahead to see how they are that day, so you know what to expect before you get there.
- Try greeting them with their first name. If their dementia is progressing, they could find being

called Mum or Grandad confusing. The person may not always recall their relatives name or names, but will generally sense that they are important to them.

- Let the person living with dementia lead the way at the visit. Ask them if they would like to sit in the lounge or their room; if they would like tea or coffee; if they would prefer to have a stroll inside or outside.





- If you can, carry on doing the things you used to do. If you both used to read the papers over breakfast, take two copies of the same newspaper so that you can talk about the articles that interest you both.
- Bring along a job that needs doing. Maybe you have some peas that need shelling or flowers that need arranging. It will give you both something to talk about, as well as a real sense of purpose.
- Do a project together that you can pick up on each visit, like knitting a scarf, following a tapestry project or making a collage, something you'll both look forward to and talk about.
- Try playing a favourite game like Scrabble, bridge or whist. Be careful not to add extra stress if your loved one has trouble keeping track of the game. It's fine not to follow all the rules — joining in and enjoying the activity matters more.
- Enjoy quiet time sitting in the garden, eating a meal together or looking at letters and photos.

## Bringing younger children along

People living with dementia can often respond well to children, so never feel that you should leave your child at home when planning a trip to visit a loved one.

To make your visit especially rewarding for young and old alike, try these five tips.



**1** **Call ahead.** If your loved one lives in a care home, see if there is a particularly good day to visit with your child. Maybe they have animals visiting or a baking class the child could join in with.

**2** **Pack plenty of toys**, but leave the noisy ones at home. Search out any toys that the child and loved one can enjoy together, like completing a jigsaw or sharing a book.

**3** **Take some sweets** for the resident to give to their youngest visitor. Who doesn't like grandma's sweetie tin?

**4** **Encourage the child to make something** meaningful for the person they are visiting.

A drawing, homemade treat or a simple model - these gestures are often warmly received.

**5** **Get out in the garden.** See if the family can help with any deadheading, weeding or simply smelling the flowers or tasting the produce.

If your loved one enjoyed animals throughout their life, why not bring a four-legged friend along? Spending time with animals may be especially beneficial for someone who has more difficulty communicating.



# Uncomfortable conversations



There are so many ways to connect with a loved one living with dementia, but you may still have days when you experience difficult conversations.

Don't blame yourself or the person living with dementia. They're doing the best they can with a brain that's working differently now. If they seem irritable or upset, it's often a sign that they're struggling or that something feels too much for them.

It's also worth considering if they may be feeling overwhelmed or in pain. Even low level aches and pains can affect our ability to connect with others.

In our survey, we found that the three biggest challenges people faced when communicating with someone with dementia were:

**1. Having to repeat themselves (43%)**

**2. Their loved one not knowing who they are (42%)**

**3. Understanding exactly what their loved one means (40%)**

# Try these five tips for managing difficult conversations

## 1 Try not to take it personally.

It's important to try to understand the cause behind their reaction so you can approach the situation differently next time.



## 2 Try to understand what they are feeling.

Anger might seem like an extreme reaction to you, but it's often your loved one's way of expressing themselves when words are difficult. For example, banging a table may simply be a way of showing impatience or frustration.



**3 Offer reassurance.** Don't try to convince your loved one that you are a close relative or that they are imagining things. Instead, listen to them, look them in the eye and ask closed questions to understand their concerns. Take their complaints seriously.





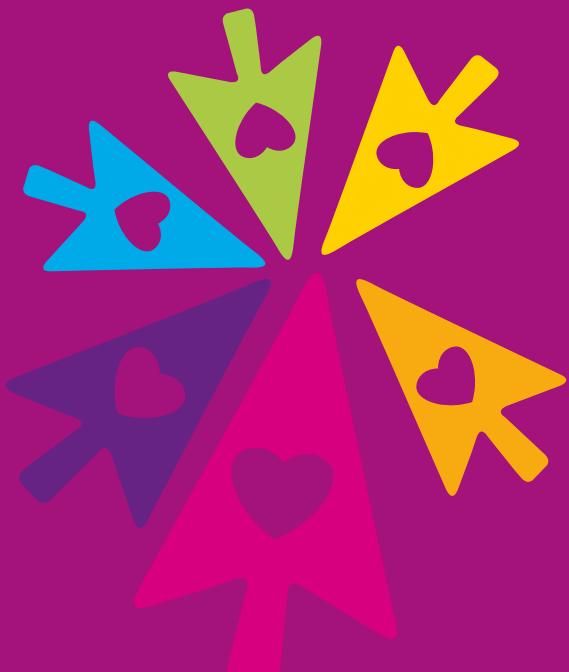
**4** **Don't try to correct or challenge.** If your loved one wants to go home and that is not possible, ask them questions about their home – "How many bedrooms did your house have?", "Did you have a garden?", "Who were your neighbours?". They may be able to answer these questions better, and in doing so they'll bring back happy memories. Or, if your loved one is looking for someone who passed away several years ago, don't correct them. Instead, ask questions about the person. "What is his name?" "How did you meet?" "Where did you get married?"



**5** **Remember that they can't always regulate their behaviour.** Sometimes, the personality of a person with dementia will appear to change radically, and they may seem to behave very differently, including swearing or being unpleasant to others. This is usually a result of changes in the brain caused by dementia that affect the ability to regulate actions and responses in different situations. Although this can be difficult, it is important to respond calmly and avoid taking it personally.



# Staying connected without words



As dementia progresses and verbal communication becomes less effective, other senses can play a larger role in how people with dementia express themselves.

Facial expressions, visual cues, familiar scents and a reassuring hand on theirs can all help you to remain connected without using words.

If your loved one doesn't speak to you, it doesn't mean they don't want to listen

to you. If your words are misunderstood, use cues and clues to deliver your message. Always respect their personal space, however, if they want to be left alone, or have quiet time.



## Sight

While you're speaking, using visual cues can be helpful for someone living with dementia. For example, use pictures of the people or places you're talking about. Photos of familiar places, such as holiday destinations and workplaces; or significant items

associated with hobbies, such as gardening equipment or dance shoes, can be helpful conversation starters.

It's also useful to gesture to the objects you're talking about. Hold up a cup when asking a person if they would like



a drink of tea. If you're helping them to decide between two jumpers, lay them both out to give a visual choice.

And don't forget about your own body language and facial expressions. These can share a lot of information — and you can also learn from watching your loved ones.

### How sight can change with dementia

Dementia can affect the parts of the brain that process what the eyes see, so your loved one may find it harder to distinguish colours or recognise familiar objects. This can be confusing or upsetting, so it's helpful to avoid activities that rely heavily on visual perception.

At times, a person's actions may indicate that they are not able to see

objects around them. In many cases, the eyes are healthy — it's the brain that has trouble making sense of what is seen. For example, someone may be unable to find a cup of tea in front of them without help.

It is also important to be aware that our eyesight generally deteriorates as part of natural ageing, which can add to these challenges.



## Hearing

Sounds are often closely tied to memories, and something as simple as your voice can remain familiar to a person living with dementia even if they don't recognise you. If a conversation isn't flowing, you could try reading to your loved one, especially from books with rhythmic patterns like hymns and poems.

Music can also be incredibly important. A playlist of familiar songs

can be a great way to connect with your loved one.

Familiar sounds can be useful for a person living with dementia, too, such as the clatter of plates at dinnertime. However, remember that background noise is best kept to a minimum. When there is a lot of background noise, a person with dementia may struggle to understand what is being said or appear to ignore others.



## Smell and taste

Scents and tastes can have so many benefits, from evoking happy memories to having a relaxing influence. Try burning scented candles and guessing the smell together, sniffing flowers in the gardens, doing a spot of baking, tasting fruit with your eyes closed or putting on a scent you used to wear.

Sensory gardens can be fantastic spaces to enjoy the fresh air while engaging the senses. For many, the scents of the herbs and the taste of fresh grown vegetables have a calming effect.



## Touch

Physical touch can be an effective way of communicating — but never force it. A once-formal person might become more tactile as their dementia progresses, whereas someone who used to be affectionate

might become more reserved. Be as tactile as your loved one wants you to be.

If physical touch has a calming and reassuring effect, offering something



simple like a massage or manicure can be an easy way to achieve this. Receiving caring attention from another person can be hugely powerful, offering a person living with dementia affection and reassurance that makes them feel valued.

### **Namaste care – what is it and how can it help?**

At Care UK, we offer Namaste care to residents. Namaste is a specialised, sensory care approach for individuals living with advanced dementia.

These sessions are delivered by trained carers and incorporate gentle, personalised touch — such as hand or foot massages — accompanied by soothing music and calming scents. For individuals who have become physically withdrawn, are experiencing high levels of distress, or are

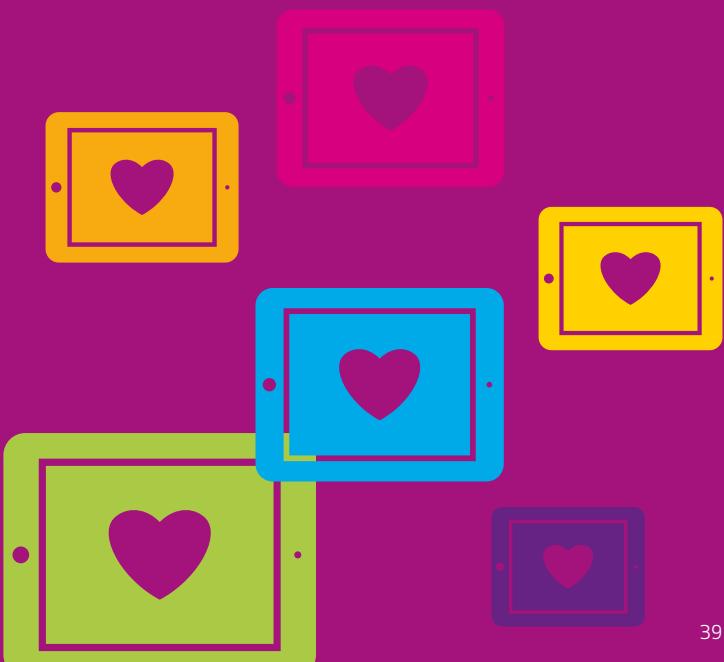


approaching the end of life, Namaste Care can provide a meaningful sense of connection and comfort, tailored to their unique needs.

**“45% of respondents to our survey said they were most worried about their loved one feeling lonely.”**



# Additional support and advice



For more information about Care UK and our homes and services, visit our website, [careuk.com](http://careuk.com).

### Looking after yourself

Caring for a person who is living with dementia is a very demanding role. Make sure you have some time for yourself, and consider joining some support groups, calling on experts for help and asking friends and family members for their support too.

By sleeping at night, eating well, having a life outside of dementia care and having a support network, you will be able to communicate much more positively with the person you love. And that will make such a difference to you both.

If you're a full-time family carer, have you considered a respite care break? Many Care UK care homes offer short-term care for older people while their



regular carer takes a well-earned break. Some Care UK homes also run adult day clubs, which offer a welcoming place where people living with dementia can make friends and have fun while their family carers take some time to themselves.

## Finding the right dementia care and support

At Care UK, we understand that every journey with dementia is unique. That's why we are here to help you find the right care options for your loved one, with personalised plans and compassionate support every step of the way.

For more information about Care UK care homes, visit [careuk.com](http://careuk.com). On our website you'll also find a series of free guides and help and advice articles offering tips for caring for someone living with dementia, as well as advice on choosing a care home.

**[Visit careuk.com/help-advice/  
dementia-help-advice](http://careuk.com/help-advice/dementia-help-advice)**

Our expert-led campaign The Big Dementia Conversation is another way we provide a hub for sharing knowledge and real-life experiences to support those who are looking after someone living with dementia.

Many care homes around the UK hold regular support sessions for family carers, as well as dementia awareness sessions. Care home teams are also frequently involved with local dementia charities and work to create dementia-friendly environments throughout their communities.

Search for your local care home to find out more about the care and events they offer.

**[Visit careuk.com/care-homes](http://careuk.com/care-homes)**



# Other sources of advice and support

Health and social care professionals can offer information, advice and care to people with dementia and their carers. The services available and how they are organised vary by area. For more information on what is available locally contact your local social services department or GP surgery.

Here are a few other organisations that may be able to provide help and advice:

## **Age UK**

Age UK has been helping older people across the UK for more than 60 years.

[ageuk.org.uk](http://ageuk.org.uk)

## **Alzheimer Scotland**

Alzheimer Scotland offers a wide range of specialist services for people with dementia and their carers.

[alzscot.org](http://alzscot.org)

## **Alzheimer's Society**

For support, information, advice and local services for those caring for someone with dementia.

[alzheimers.org.uk](http://alzheimers.org.uk)

## **Care Information Scotland**

For information about care services for older people living in Scotland.

[careinfoscotland.co.uk](http://careinfoscotland.co.uk)



### **Carers UK**

Offers advice on benefits and services available to carers.

[carersuk.org](http://carersuk.org)

### **Dementia Adventure**

Connecting people living with dementia with the outdoors.

[dementiaadventure.co.uk](http://dementiaadventure.co.uk)

### **Dementia UK**

Family carers and people living with dementia are at the heart of what they do.

[dementiauk.org](http://dementiauk.org)

### **Regulators**

#### **Care Quality Commission (CQC)**

The CQC is the health and social care regulator for England.

[cqc.org.uk](http://cqc.org.uk)

#### **Care Inspectorate Scotland**

The Care Inspectorate regulates care services in Scotland.

[careinspectorate.com](http://careinspectorate.com)

#### **Care Inspectorate Wales**

The Care Inspectorate regulates care services in Wales.

[careinspectorate.wales](http://careinspectorate.wales)

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