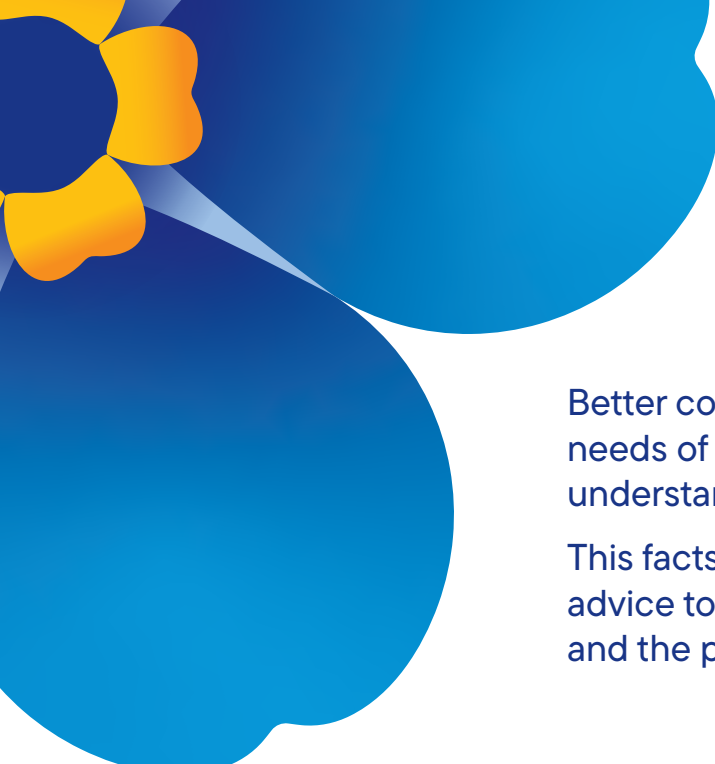


Communicating



Together we are help & hope
for everyone living with dementia



Better communication can make it easier to meet the needs of the person with dementia, and for you to understand each other.

This factsheet is written for carers and gives tips and advice to support good communication between you and the person with dementia.

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1 Communication and dementia

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Good communication is an important part of living well after a diagnosis of dementia. It helps people with dementia to keep a sense of self, sustain relationships and maintain their quality of life. Even as communicating becomes more challenging, there are lots of ways to communicate meaningfully together.

You and the person you care for will have to change how you communicate with each other as their dementia progresses. This can be upsetting and frustrating for the person with dementia and their carers, friends and family. If the person with dementia is not able to express themselves, they can lose confidence, feel anxious or depressed, or become withdrawn.

They may have trouble finding the right word, repeat words and phrases, or use one word when they mean another. Because they are unable to communicate in the way they are used to, you may find that they get frustrated or that their behaviour becomes challenging or difficult to understand.

As well as difficulties with how they use words and language, people with dementia are likely to have sight or hearing problems, which can also make it harder to communicate. This factsheet has tips and advice for communicating in ways that are right for the person with dementia.

As more people use smartphones and tablets, you might find that you and the person you care for communicate more through video calls. Seeing your facial expressions and body language can be more helpful to a person with dementia than a telephone call or text message. Many of the tips and advice in this factsheet will be helpful for video calling. For more information on the technology needed for this see factsheet 437, **Using technology to help with everyday life**.

Talking about the impact of caring can help. Talk to a friend or family member, or to a professional, such as a counsellor or dementia adviser. Call our **Dementia Support Line** on **0333 150 3456** or talk to other carers on our **Dementia Support Forum** – go to **forum.alzheimers.org.uk**

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I kept seeing that look of confusion on my husband's face when I asked him to 'put the kettle on'. I have learnt the hard way. Now I ask him to 'put some water in the kettle' and he has no problems.

Partner of a person with dementia

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2 Dementia and language

A person with any type of dementia can have problems with language. This is because dementia can damage the parts of the brain that control language. How and when language problems develop will depend on:

- their personality and the ways they manage these language problems
- the type of dementia they have
- the stage of the dementia.

Language problems can also vary from day to day, or be more or less of a problem at different times of the day. They can be made worse if the person is tired, in pain or unwell. The surroundings can also help with communication, or make it more difficult.

In some types of dementia, such as some forms of frontotemporal dementia (FTD), a person may start to have problems with language much earlier than other types of dementia. It is likely to be one of the first symptoms that is noticed. For more information on FTD see factsheet 404,

What is frontotemporal dementia (FTD)?

Dementia can affect how a person communicates and the language they use. They may:

- not be able to find the right words
- use a related word (for example, 'book' instead of 'newspaper')
- use substitutes for words (for example, 'thing that you sit on' instead of 'chair')
- not find any word at all
- not struggle to find words, but use words that have no meaning, or that are jumbled up in the wrong order
- go back to the first language they learned as a child. For example, if they learned English as a second language, they may forget how to speak it.

Dementia can also affect the person's ability to respond appropriately or follow a conversation. This could be because they do not understand what you have said, have less ability to keep focused or are unable to put the correct words together as a reply.

There may eventually come a time when the person can no longer communicate as they once did. This can be distressing and frustrating for them and those supporting them, but there are ways to keep communicating. For example, the person may be able to express themselves through body language and other non-verbal ways (see 'Non-verbal communication' on page 7).

Dementia can also affect the way a person thinks, which will have an effect on language. A person with dementia may think more slowly, lose focus or not be able to understand complex ideas. For example, they may take longer to process thoughts and work out how to respond to what is being said. They may also move from one topic to another without finishing a sentence as it becomes harder for them to focus.

Communication for a person with dementia can be affected by pain, discomfort, illness or the side effects of medication. If you notice a sudden change in the person (over hours or days), it could be delirium, which is a medical emergency. You should make an urgent appointment with the GP or call the NHS 111 telephone service. Say that the person has changed suddenly, or no longer seems to be acting like their usual self.

If a person with dementia is living in a care setting or staying in hospital, any communication problems they have can affect the care and support they receive. Alzheimer's Society produces a simple form called 'This is me' to help record personal information about a person. This includes how they like to communicate, any difficulties they have, and how care and support staff can tailor their care for them as an individual.

To order a free copy of 'This is me', email **orders@alzheimers.org.uk** or call **0300 303 5933**. 'Dyma Fi' is also available in Welsh.

There are other reasons communicating with a person with dementia can be difficult. For example, the person may:

- make comments that you or others feel are inappropriate for the situation
- repeat themselves or ask the same question over and over
- believe things that aren't true.

For more on these problems and how to manage them see factsheet 525, **Changes in behaviour** and booklet 600, **Caring for a person with dementia: A practical guide**.

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3 Tips for communicating with a person with dementia

These tips apply to however the person usually communicates, for example speaking English or signing British Sign Language. Every person's experience of dementia is unique, so not every tip may be helpful to the person you care for. Use the tips that you feel will improve communication between you.

Before you communicate

- Think about how you might feel if you struggled to communicate, and what would help.
- Make sure you're in a good place to communicate. Ideally it will be quiet and calm, with good lighting. Busy environments can make it especially difficult for a person with dementia to concentrate on the conversation, so turn off distractions such as the radio or TV.
- Plan enough time to spend with the person. If you feel rushed or stressed, take some time to become calmer beforehand.
- Think about previous conversations you have had with the person and what helped you to communicate well then.
- Think about what you are going to talk about. It may be useful to have an idea for a particular topic ready.
- If you are not sure what to talk about, you can use the person's environment to help – anything that they can see, hear or touch might be of interest.
- If there is a time of day where the person is able to communicate more clearly, try to use this time to ask any questions or talk about anything you need to.
- If the person has begun to communicate using the first language they learned, and you do not speak it, consider arranging for family members or friends who also speak the language to be there with you. If the person prefers reading, try using translated written materials. A translation or interpretation app on a smart phone or tablet can translate between you if you don't speak the same language. If you need an interpreter, speak to your local authority, the person's care home, or an organisation such as the Institute of Translation and Interpreting (see 'Other useful organisations' on page 12).
- Make the most of 'good' days and find ways to adapt on more difficult ones.

- Make sure any of the person's other needs are met before you start – for example, ensuring they are not in pain or hungry.
- Get the person's full attention before you start.

Listening

- Listen carefully to what the person is saying. Offer encouragement both verbally and non-verbally, for example by making eye contact and nodding. This 'active listening' can help improve communication.
- The person's body language can show a lot about their emotions. The expression on their face and the way they hold themselves can give you clear signals about how they are feeling when they communicate.
- If you haven't fully understood what the person has said, ask them to repeat it. If you are still unclear, rephrase their answer to check your understanding of what they meant.
- If the person with dementia has difficulty finding the right word or finishing a sentence, ask them to explain it in a different way. Listen and look out for clues. If they cannot find the word for a particular object, ask them to describe it instead.
- Allow the person plenty of time to respond – it may take them longer to process the information and work out their response.
- Try not to interrupt the person – even to help them find a word – as it can break the pattern of communication.
- If the person is upset, let them express their feelings. Allow them the time that they need, and try not to dismiss their worries – sometimes the best thing to do is just listen, and show that you are there.

How to communicate

- Stand or sit where the person can see and hear you as clearly as possible – usually this will be in front of them, and with your face well-lit. Try to be at eye-level with them, rather than standing over them.
- Sit as closely to the person as is comfortable for you both, so that you can clearly hear each other, and make eye contact as you would with anyone.
- Communicate clearly and calmly.
- Go at a slightly slower pace than usual if the person is struggling to follow you.
- Use short, simple sentences.
- Don't talk to the person as you would to a child – be patient and have respect for them.

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Like many with dementia and others, when I'm in a noisy situation it's hard for me to concentrate.

Person with dementia

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- Allow time between sentences for the person to process the information and respond. These pauses might feel uncomfortable if they become quite long, but it is important to give the person time to respond.
- Try to be conversational, rather than asking question after question, which may feel quite tiring or intimidating.
- Try to let the person complete their own sentences, and try not to be too quick to assume you know what they are trying to say.
- Include the person in conversations with others. It is important not to speak as though they are not there. Being included can help them to keep their sense of identity and know they are valued. It can also help them to feel less excluded or isolated.
- If the person becomes tired easily, then short, regular conversations may be better.
- Prompts can help, for instance pointing at a photo of someone or encouraging the person to hold and interact with an object you are talking about.
- Try to make sure your body language is open and relaxed.
- Avoid speaking sharply or raising your voice.

What to communicate

- Try to avoid asking too many questions, or asking complicated questions. The person may become frustrated or withdrawn if they can't find the answer.
- Try to stick to one idea at a time. Giving someone a choice is important, but too many options can be confusing and frustrating.
- Phrase questions in a way that allows for a simple answer. For example, rather than asking someone what they would like to drink, ask if they would like tea or coffee. Questions with a 'yes' or 'no' answer are easier to answer.
- If the person doesn't understand what you're saying even after you repeat it, try saying it in a slightly different way instead.
- If the person is finding it hard to understand, consider breaking down what you're saying into smaller chunks so that it is more manageable.
- Try to laugh together about misunderstandings and mistakes. Humour can help to relieve tension and bring you closer together. Make sure the person doesn't feel you are laughing at them.

4 Non-verbal communication

Non-verbal communication is communicating without the use of spoken words. You could use gestures, facial expressions and body language to communicate with the person you care for. These may become some of the main ways a person communicates as their dementia progresses. Non-verbal communication may be especially important if they start communicating in the first language they learned, and you do not understand or speak this language.

If a person is finding any kind of conversation too difficult, there may be other ways that they can communicate their emotions. Art therapies and activities such as drawing, painting, music, poetry and drama can help a person with dementia to express themselves. For more information see booklet 77AC, **The activities handbook**.

During the later stages of dementia, the person may not be able to communicate much at all. It may still be helpful to talk to the person, and communicate by touch if it feels appropriate, for example by holding their hand. Even if they don't respond very much, or at all, they may feel a level of connection with you and a sense of comfort.

Tips for non-verbal communication with a person with dementia

These tips can help with non-verbal communication with a person with dementia.

- Use physical contact to communicate your interest and to provide reassurance – don't underestimate the reassurance you can give by holding the person's hand or putting your arm around them, if it feels appropriate.
- Try not to sit too close to the person or stand over them to communicate – it can feel intimidating. Instead, respect their personal space and try to sit or stand at eye level.
- The person with dementia will read and interpret your body language. Sudden movements, the tone of your voice or a tense facial expression can upset or distress them, even if the words you say are not upsetting.
- Make sure that your body language and facial expression match what you are saying, even if this might feel a bit forced at times. For example, it can be useful to smile when talking about pleasant memories.

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Tom has no speech now. He can't smile, so he cries, which means he recognises you.

Partner of a person with dementia

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We had a lovely call from my brother and baby last night, Mum is very used to FaceTime and she had a great time making faces at the baby, cooing and copying the baby's expressions.

Family member
of a person with
dementia

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- Try to learn to recognise what a person is communicating through their body language. Try to keep them engaged if they seem distracted or bored.
- Visual prompts can be very helpful. For example, cue cards or a book of pictures of meals that a person can point to, to communicate what they'd like to eat. Technology can also help with this through apps that show pictures or videos of different types of foods. This can help the person communicate as well as stimulate their appetite. For more information see factsheet 437, **Using technology to help with everyday life**.
- The person may enjoy drawing or singing to express themselves. To find out what local activity groups are running in your area, you can search at **alzheimers.org.uk/dementiadiirectory**

5 Sensory impairment

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Many people with dementia will have some kind of sensory impairment, such as sight loss, hearing loss, or both. People with sensory impairment and dementia together are likely to have more difficulties with their communication. However, there is still a lot you can do to understand each other.

Hearing loss

Most people aged over 70 will have some hearing loss. They may consider themselves deaf, 'hard of hearing' or having 'acquired hearing loss'. This may be due to age-related damage to the ears, or other causes such as noise damage, infection, diseases or injury.

People who are born deaf or become deaf at a young age may use British Sign Language (BSL) as their first language and identify with the Deaf community.

How a person with hearing loss communicates will depend on:

- the type of hearing loss they have
- whether they use a hearing aid, speak British Sign Language, lip-read or a use combination of these
- their personal preference and life history.

People with hearing loss are likely to experience more difficulties as a result of their dementia. They may already find it harder to communicate. Not being able to hear what is going on around them or hear other people speak can add to their confusion. Dementia and hearing loss can also make people feel socially isolated, so having both conditions at once can be very difficult for someone. This makes good communication even more important.

Alzheimer's Society has information in British Sign Language online. Watch the videos at **alzheimers.org.uk/get-support/publications-factsheets-accessible-resources/information-in-your-language/dementia-information-bsl**

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Tips for communicating with someone with dementia and hearing loss

These tips can help with communication with a person with dementia who has hearing loss.

- If the person uses a hearing aid, check that it is fitted and working properly. If you think the hearing aid isn't working or if you need help checking it, speak to the GP or make an appointment with the audiology department at your local hospital.
- It may be helpful to check if the person has too much ear wax, as this may make any hearing loss and communication difficulties worse.
- Ask the person if they would like to lip-read.
- Turn your face towards the person and ensure your face is well-lit so your lip movements can be easily seen.
- Don't shout or over-exaggerate words or lip movements. This can actually make it harder for the person to understand you.
- Speak clearly and slightly slower, but keep the natural rhythms of your speech.
- Don't cover your mouth.
- Consider using visual prompts, such as objects or pictures to help.

Sight loss

Many people have some sight loss as they get older. This may be age-related, or due to a condition such as cataracts or age-related macular degeneration (AMD). Many people with sight loss will need glasses to help them see.

People with sight loss are likely to experience more difficulties as a result of their dementia. Not being able to see what is around them can lead to a greater sense of disorientation, as well as worse mobility and a higher risk of falls. Having both dementia and sight loss can also make people feel isolated from those around them, which makes good communication even more important.

Communicating with a person with dementia and sight loss may be difficult, as the person may not be able to pick up on non-verbal cues or follow a conversation as easily. There are a number of things you can do to help them.

Audio information

Alzheimer's Society has information and advice about dementia in audio format and on CD. You can listen online to this, as well as or stories from other people affected by dementia, at alzheimers.org.uk/about-us/news-and-media/audio-and-video

Tips for communicating with someone with dementia and sight loss

These tips can help with communication with a person with dementia and sight loss.

- Check the person is wearing their glasses, if needed, and that these are clean and the prescription is up-to-date.
- If someone has more than one pair of glasses, make sure they are clearly labelled for the activity they are used for – for example, reading glasses.
- Introduce yourself or try to get the person's attention before starting or ending a conversation. If you don't, they may become confused about who is talking, or if they are being spoken to.
- If you are helping the person with a task, let them know what you are going to do before and during it.
- Use reference points when describing where something is – for example, 'Your water is on the table to your right'. It may be helpful to use imaginary hands on a clock face to describe where something is, especially for people who have lived with sight loss for many years – for example, 'The cup is in front of you at 12 o'clock'.
- Make sure the physical environment is not making communication difficult – for example, make sure that the lighting is consistent and can be adjusted. Try to reduce shadows as the person may mistake them for obstacles.
- If you are communicating with someone in writing, such as sending them a letter or writing an email, think about the colour of the background and font size (for example, black text on a yellow background often makes text easier to read, as does larger text). If they have a mobile phone, you could also change the settings with their permission to make text messages easier to read.
- Around 1 in 10 people with learning disabilities have serious sight problems. They are also at greater risk of developing dementia at a younger age, particularly people with Down's syndrome. You should make sure a person with learning disabilities and dementia has a communication passport – this gives information about a person's complex communication difficulties, including the best ways to communicate with them. For more information see factsheet 430, **Learning disabilities and dementia**.

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Other useful organisations

DemTalk

www.demtalk.org.uk

DemTalk is a free online toolkit that gives guidance on communication with people living with dementia.

Hearing Link

0184 434 8111

helpdesk@hearinglink.org

www.hearinglink.org

Hearing Link is an organisation dedicated to improving the quality of life for those who are hard of hearing. They provide wallet communication cards which can be helpful.

Institute of Translation and Interpreting (ITI)

0190 832 5250

info@iti.org.uk

www.iti.org.uk

ITI is an independent professional membership association who can help find practising translators, interpreters and language service providers.

Royal College of Speech and Language Therapists (RCSLT)

020 7378 3012 (8am–5pm Monday–Friday)

info@rcslt.org

www.rcslt.org

RCSLT is the professional body for speech and language therapists in the UK. They can assist you in finding an independent speech and language therapist in your area.

Royal National Institute of Blind People (RNIB)

0303 123 9999 (8am–8pm Monday–Friday, 9am–1pm Saturday)

helpline@rnib.org.uk

www.rnib.org.uk

RNIB is one of the UK's leading sight loss charities and the largest community of blind and partially sighted people.

Royal National Institute of Deaf People (RNID)

0808 808 0123 (helpline, 8.30am–5pm Monday–Friday)

Text Relay – call 18001 0808 808 1230

contact@rnid.org.uk

www.rnid.org.uk

RNID provide information and support to people affected by hearing loss and tinnitus.



Factsheet 500

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At Alzheimer's Society we're working towards a world where dementia no longer devastates lives. We do this by giving help to everyone who needs it today, and hope for everyone in the future.

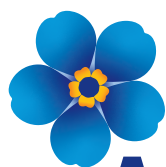
We have more information on **Living with dementia**.

For advice and support on this, or any other aspect of dementia, call us on **0333 150 3456** or visit **alzheimers.org.uk**

Thanks to your donations, we're able to be a vital source of support and a powerful force for change for everyone living with dementia. Help us do even more, call **0330 333 0804** or visit **alzheimers.org.uk/donate**



Patient Information Forum



**Alzheimer's
Society**

Together we are help & hope
for everyone living with dementia

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