

Communicating

We all need to communicate with other people. We need to tell other people a wide range of things, including our needs, wishes and feelings. How well we can communicate will affect our quality of life, as well as how much we are able to keep our individuality and sense of identity.

Dementia can make it hard for people to communicate, and this can be upsetting and frustrating for them and those around them. However, there are many ways to help you support and communicate with each other. This factsheet gives tips and advice for communicating with someone with dementia, and supporting them to communicate in whichever way works best for them.

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Communicating

A person with dementia may have trouble finding the right word, they may repeat words and phrases, or may become 'stuck' on certain sounds. In addition, people with dementia are likely to have other sensory impairments (such as sight or hearing problems) which can also make it harder to communicate. If someone is not able to express themselves properly, they can lose confidence, or feel anxious, depressed or withdrawn. They may also behave in ways others find odd, because they are trying to communicate what they can no longer say with words.

Dementia and language

Problems with language can occur in all forms of dementia. This is because the diseases that cause dementia can affect the parts of the brain that control language. How and when language problems develop will depend on the individual, as well as the type of dementia and the stage it is at. These problems will also vary day to day. In some forms of dementia – such as frontotemporal dementia – it is very likely to be one of the first symptoms that is noticed.

One sign that a person's language is being affected by dementia is that they can't find the right words. They may use a related word (eg 'book' for 'newspaper'), use substitutes for words (eg 'thing to sit on' instead of chair) or may not find any word at all. Another sign is that they may continue to have fluent speech, but without any meaning – for example, they may use jumbled up words and grammar. Dementia can also affect the person's ability to make an appropriate response, either because they may not understand what you have said or meant.

There may eventually come a time when the person can hardly communicate at all using language. This can be distressing for them and those supporting them, but there are ways to maintain communication and support the person to express themselves.

Dementia can also affect a person's cognitive abilities. A person with dementia may have slower speed of thought, or not be able to understand complex ideas. This can also affect their ability to communicate. For example, they may take longer to process thoughts and work out how to respond to what is being said.

Other factors can affect a person with dementia's communication, including pain, discomfort, illness or the side-effects of medication. If you suspect this might be happening, talk to their GP.

If a person with dementia is living in a hospital or care setting, any problems they have communicating can affect the care and support they receive. Alzheimer's Society produces a document called 'This is me' which can give information about a person, including how they like to communicate, any difficulties they have, and how care and support staff can best help them to communicate. To order a free copy email orders@alzheimers.org.uk or call 0300 303 5933.

Tips: communicating with someone with dementia

Before you speak

- Make sure you're in a good place to talk – quiet, with good lighting and without too many distractions (eg no radio or TV on in the background).
- Get the person's full attention before you start.
- Position yourself where the person can see you as clearly as possible (eg with your face well-lit) and try to be on the same level as the person, rather than standing over them.
- Sit close to the person (although not so close you are in their personal space) and make eye contact.
- Make sure your body language is open and relaxed.
- Have enough time to spend with the person. If you feel rushed or stressed, take some time to calm down.
- Think about what you are going to talk about. It may be useful to have an idea for a particular topic ready. You can also use the person's environment to stimulate topics.
- If there is a time of day where the person will be more able to communicate (eg in the morning) try to use this time to ask any questions or talk about anything you need to. Make the most of 'good' days and find ways to adapt on 'bad' ones.
- Make sure any of the person's other needs are met before you start (eg they're not hungry or in pain).

How to speak

- Speak clearly and calmly.
- Speak at a slightly slower pace, and allow time between sentences for the person to process the information and respond. This might seem like an uncomfortable pause to you, but it is important for helping the person to communicate.
- Avoid speaking sharply or raising your voice.
- Use short, simple sentences.
- Try to communicate with the person in a conversational way, not question after question (it can feel like an interrogation).
- Don't talk about the person as if they are not there or talk to them as you would to a young child – be patient and have respect for them.
- Try to laugh together about misunderstandings and mistakes – it can help. Humour can help to bring you closer together, and may relieve the pressure. However, be sensitive to the person and don't laugh at them.
- Include the person in conversations with others. This may be easier if you adapt what you say slightly. Being included can help a person with dementia to keep their sense of identity and feel they are valued. It can also help to reduce feelings of exclusion and isolation.

What to say

- Try to avoid asking too many questions, or complicated questions. People with dementia can 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.
- 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.
- Ask questions one at a time, and phrase them in a way that allows for a 'yes' or 'no' answer (eg rather than asking someone what they would like to do, ask if they would like to go for a walk) or in a way that gives the person a choice (eg 'would you like tea or coffee?').
- Rephrase rather than repeat, if the person doesn't understand what you're saying. Use non-verbal communication to help (eg pointing at a picture of someone you are talking about).
- If the person becomes tired easily, it may be better to opt for short, regular conversations.
- As dementia progresses, the person may become confused about what is true and not true. If the person says something you know is not true, try to find ways of steering the conversation around the subject and look for the meaning behind what they are saying, rather than contradicting them directly. For example, if they are saying they need to go to work is it because they want to feel useful, or find a way of being involved and contributing? Could it be that they are not stimulated enough?

Listening

- Listen carefully to what the person is saying, and offer encouragement.
- If you haven't understood fully, rephrase what you have understood and check to see if you are right. The person's reaction and body language can be a good indicator of what they've understood and how they feel.
- 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 out for clues. Also pay attention to their body language. The expression on their face and the way they hold themselves can give you clear signals about how they are feeling.
- Allow the person plenty of time to respond – it may take them longer to process the information and work out their response. Don't interrupt the person as it can break the pattern of communication.
- If a person is feeling sad, let them express their feelings. Do not dismiss a person's worries – sometimes the best thing to do is just listen, and show that you are there.

Body language and physical contact

- Non-verbal communication is very important for people with dementia, and as their condition progresses it will become one of the main ways the person communicates. You should learn to recognise what a person is communicating through their body language and support them to remain engaged and contribute to their quality of life.
- A person with dementia will be able to read your body language. Sudden movements or a tense facial expression may cause upset or distress, and can make communication more difficult.
- Make sure that your body language and facial expression match what you are saying.
- Never stand too close to someone or stand over them to communicate – it can feel intimidating. Instead, respect the person's personal space and drop to or below their eye level. This will help the person to feel more in control of the situation.
- 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.

Sensory impairment

A number of people with dementia will have some form of sensory impairment (such as sight loss, hearing loss or both). People with both sensory impairments and dementia are likely to have additional difficulties with their communication. However, there is still a lot you can do to help them communicate effectively.

All of the tips and suggestions in this factsheet may be useful for people with dementia who have difficulties communicating. A number of additional suggestions for people with sensory impairments are outlined below.

Hearing loss

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

In comparison, people who are born deaf or become deaf at a young age are considered to have 'profound deafness'. They may consider themselves as Deaf (often referred to as Deaf with a capital D), 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 a range of factors including:

- the type of hearing loss they have
- whether they use a hearing aid, BSL, lip-reading or a combination of all of them
- personal preference and life history.

There are strong links between dementia and hearing loss that suggest hearing loss can make developing dementia more likely.

People with hearing loss are likely to experience more difficulties as a result of their dementia. They may already find it harder to communicate, and not being able to hear what is going on around them or hear other people speak can add to their confusion. Both 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 extremely important.

Tips: Communicating with someone with 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 your GP or make an appointment with the audiology department at your local hospital.
- 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 clues such as objects or pictures to help.
- 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.

Sight loss

Many people experience some degree of sight loss as they get older. It is estimated that 1.6 million people over 65 are living with sight loss in the UK. This may be age-related, or due to a condition such as cataracts or age-related macular degeneration. 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 and distress, as well as decreased mobility and a risk of falls. Having both dementia and sight loss can also make people feel isolated from those around them. This makes good communication extremely 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 is a lot you can do to help them.

Tips: Communicating with someone with sight loss

- Check the person is wearing their glasses, if needed, and that these are clean and that the prescription is up-to-date.
- If someone has more than one pair of glasses, ensure they are labelled or marked for the activity they have to be used for – for example, reading glasses.
- Introduce yourself or try to gain the person's attention before starting or ending a conversation. If you don't, they may become confused about who is talking, be unsure if they are being spoken to, and may not know if people enter or leave the room.
- If you are helping the person with a task, let them know what you are going to do before and during it.
- Use references when describing where something is – for example, your water is on the table on 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 (eg the cup is in front of you at 12 o'clock position).
- Make the most of the physical environment – for example, make sure there is good lighting, which is consistent, even and can be adjusted. Try to reduce shadows as the person may mistake them for obstacles.
- The person may not be able to pick up on non-verbal communication, such as body language. Bear this in mind when talking to them.
- If you are communicating with someone in writing, such as sending them a letter, think about the colour of paper and font size (for example, black text on white or yellow paper often makes text easier to read, as does larger text).
- People with learning disabilities are 10 times more likely to have serious sight problems than other people. 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 – a practical tool that gives information about a person's complex communication difficulties, including the best ways to communicate with them.

Other useful organisations

Action on Hearing Loss

19-23 Featherstone Street
London EC1Y 8SL

0808 808 0123
informationline@hearingloss.org.uk
www.actiononhearingloss.org.uk

Action on Hearing Loss (formerly RNID) provide information and support to people affected by hearing loss and tinnitus.

Royal College of Speech and Language Therapists

2 White Hart Yard
London SE1 1NX

020 7378 3012
info@rcslt.org
www.rcslt.org

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.

Hearing Link

27-28 The Waterfront,
Eastbourne
East Sussex BN23 5UZ

0300 111 1113
helpdesk@hearinglink.org
www.hearinglink.org

Organisation dedicated to improving the quality of life for those who are hard of hearing. They provide wallet communication cards which can be helpful.

RNIB

105 Judd Street
London WC1H 9NE

0303 123 9999
helpline@rnib.org.uk
www.rnib.org.uk

Factsheet 500

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This factsheet has also been reviewed by people affected by dementia.

A list of sources is available on request.

Alzheimer's Society National Dementia Helpline England, Wales and Northern Ireland:

0300 222 1122

9am–8pm Monday–Wednesday

9am–5pm Thursday–Friday

10am–4pm Saturday–Sunday

alzheimers.org.uk

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.

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