

Communicating with a person with dementia

Compassion is more important than truth

Advice from the Contented Dementia Trust (www.contenteddementiastrust.org)

Three Golden Rules for communicating with someone with dementia

1. ***Don't ask direct questions***
2. ***Listen to the person with dementia – and learn from them***
3. ***Don't contradict***

1. Don't ask direct questions

- Avoid asking any direct question that requires the person with dementia to search for factual information that they may no longer be able to recall. They are already aware of their disability. Asking them to search for facts they may not have will merely increase this awareness, causing them unnecessary distress and potential trauma.
- It is surprising how much information you can gather without asking direct questions!

2. Listen to the person with dementia - and learn from them

Listen to the questions the person with dementia is asking and consider very carefully what the best answer might be from their perspective rather than your own.

For people with dementia, feelings are more important than facts. It is crucial that the information they receive generates good feelings for them.

- Having a record of good feelings, yet not knowing why, is one thing.
- Having a record of negative, possibly traumatic feelings with no explanation as to why, is quite another. We owe it to the person with dementia to avoid leaving them with anxieties that they cannot, only moments later, explain.

So, we must search for the information and the language that is most acceptable to them. Once we have found the best answer to their most frequent question, this form of words should be used consistently by everyone coming into contact with the person. This may not be commonsense, but it increases confidence all round.

3. Don't contradict

Do not argue with the person with dementia about what they choose to remember and talk about.

They are increasingly likely to use intact memories from their pre-dementia past, to understand what is happening around them in the present. The rest of us need to avoid disturbing the sense they are making and start where they are at. We need to take careful note of the language they use, so that we can follow them, rather than expecting them to follow us.

The **Three Golden Rules** may seem counter-intuitive at first, but when they are used by everyone coming into contact with the person with dementia, the benefits quickly become self-evident, and life will be much easier.

Advice from the NHS (www.nhs.uk) & the Alzheimer's Society (www.alzheimers.org.uk)

Communicating with someone with dementia

Dementia is a progressive illness that, over time, will affect a person's ability to remember and understand basic everyday facts, such as names, dates and places.

Dementia will gradually affect the way a person communicates. Their ability to present rational ideas and to reason clearly will change.

If you are looking after a person with dementia, you may find that as the illness progresses, you'll have to start discussions to get the person to make conversation. This is common. Their ability to process information gets progressively weaker and their responses can become delayed.

1. Before a conversation with someone who has a dementia

Planning the conversation

You may sometimes be able to plan for conversations ahead of time. An example would be if you are visiting the person in a specific place such as a care home or hospital. Or you may want to speak with them about an important issue and want to take some time to prepare.

Plan enough time to spend with them. If you feel rushed or stressed, take some time to become calmer first.

Think about what you know about the person. How have they always communicated? What might help them if they are struggling to communicate?

There may be a time of day when they are less able to focus or communicate. Try to avoid these times for important conversations. Make the most of 'good' times and moments and find ways to adapt on more difficult ones.

Consider the environment

Communication works best in quiet and calm places, with good lighting. Busy environments can make it harder for a person with dementia to concentrate on the conversation. Ask them if you can turn off any distractions such as the radio or TV.

Stand or sit where they 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, and make eye contact as you would with anyone.

When English is not their first language

Some people with dementia can begin to communicate using the first language they learned. If this happens and you do not speak this language, consider arranging for family members or friends who also speak the language to be there with you.

You could use a translation or interpretation app on a smart phone or tablet. 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](http://www.instituteoftranslationandinterpreting.org).

If the person prefers reading, try using translated written materials.

2. During the conversation with a person that has dementia

How to engage and encourage the person with dementia

As their dementia progresses, they may seem more withdrawn, or less talkative. The way you phrase things can make a big difference in helping them join in conversations.

These tips can make it easier for them to understand and follow discussions, so they can participate and feel less isolated:

- Try to get their full attention before you start, and make eye contact.
- Make sure they are ready for a conversation. For example, make sure they are comfortable and check they are not hungry or thirsty.
- Give them time to think about what you have said. Allow time between your sentences for them to process the information and respond. These pauses might feel uncomfortable if they become quite long. However, feeling pressured to reply can stop people with dementia from responding.
- Include them 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.
- If they don't understand what you are saying, first repeat it more slowly in exactly the same way, then try saying it in a slightly different way using different words and simpler vocabulary.
- Too much information at once can be overwhelming. Try to stick to one idea or subject at a time. If they are finding it hard to understand, breaking down what you're saying into smaller chunks may be more manageable.

Listening to the person with dementia

Communication is a two-way process. As a Carer of someone with dementia, you will probably have to learn to listen more carefully to what they are saying.

Offer encouragement both verbally and non-verbally. Non-verbal encouragement could be making eye contact and nodding and using facial expression and body language.

Give them your full attention by stopping what you are doing and giving them eye contact.

Let them complete their own sentences without interrupting, even if you think you know what they are trying to say.

Acknowledge what they have said, even if they do not answer your question, or if what they say seems out of context – show you have heard them and encourage them to say more about their answer.

If they are having 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.

If you can't understand what they have said, or if they say something that doesn't make sense to you, think about what they may be trying to express. For example, they may just need reassurance or comfort in that moment.

If you still can't fully understand what the person has said, rephrase their answer to check your understanding of what they meant.

If they are 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 speak to a person with dementia

Putting some extra thought into the way you communicate can help ensure that the person gets the most out of your conversation. Remember that they may still understand a lot of what you're saying, even if they've lost some ability to respond.

- Speak clearly and calmly.
- Go at a slightly slower pace than usual if they are struggling to follow you.
- Use short, simple sentences.
- Plan short, regular conversations if they become tired easily.
- Try not to patronise or ridicule or use 'elderspeak', such as speaking in a high-pitched voice and talking down to them as though they are a child. This can be upsetting and uncomfortable.
- Avoid trying to jog their memory, and do not 'test' their memory. This can be frustrating and embarrassing for them. Instead, speak about the things you remember from the past and give them time to recall what they can with no pressure.
- **Avoid direct questions**
 - Try not to ask open questions. For example, rather than asking what they would like to drink, ask if they would like tea or coffee. Giving choices is important, but avoid too many options as this can be confusing.
 - Try to be conversational with any questions. An example might be: 'I'm going to have cake with my tea – I'll get you one too, if you like?'
- What to talk about:
 - If you are planning to visit the person, it can be useful to take some time to consider topics or subjects they may enjoy talking about.
 - With any communication, it can help to think about previous conversations you have had with them and what helped you to communicate then.
 - Prompts can help, such as using a photo of someone or encouraging them to hold and interact with an object you are talking about. You can also use their environment – anything that they can see, hear or touch might be of interest.
 - Familiar objects or things that remind the person of their past can be a nice way for them to reminisce. This may also prompt conversations about events and memories from their life.

Sometimes they may have a mistaken belief or say something that you know to be untrue. For instance, they may ask about someone who has died or may be confused about where they live. Think about whether it is really necessary to correct these beliefs. If this is not causing harm or anxiety, **then do not contradict**.

Asking questions is a good way to get the person talking. However, keep in mind that asking too many questions, or asking complicated questions, can feel tiring. They may become frustrated or withdrawn if they can't find the answer.

3. What do to when the conversation doesn't go to plan

You won't be able to plan every interaction, and not every conversation will go well. There will be times when you are in a rush, in a busy public place, or unable to get away from distractions. Remember that you can only do your best with what is in your control.

You and the person might not always understand each other. Try to laugh together about misunderstandings and mistakes. Humour can help to relieve tension and bring you closer together, although make sure they don't feel you are laughing at them.

Managing stress and working on coping skills for when you're frustrated or feeling overwhelmed can help you communicate positively with the person. If you do find yourself raising your voice or becoming angry or frustrated, step away from the situation if it's safe to do so. If this happens, be kind to yourself and focus on reconnecting with them.

4. Non-verbal communication and dementia

Communication is not just talking. Gestures, movement and facial expressions can all convey meaning or help you get a message across. Body language and physical contact become significant when speech is difficult for a person with dementia.

What is non-verbal communication?

Non-verbal communication is communicating without the use of spoken words. Most communication between people – with and without dementia – is non-verbal. It includes gestures, facial expressions and body language.

Simple words or phrases using 'common-sense' signs can be helpful for non-verbal communication. This will depend on how much the person is able to recognise gesture (or learn or remember new signs).

Why would a person with dementia use non-verbal communication?

Non-verbal communication may become the main way a person communicates as their dementia progresses. It may be especially important if they start communicating in the first language they learned, and you do not understand or speak this language.

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.

If they are 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.

During the later stages of dementia, the person may not be able to communicate much at all. It can still help to talk to them and communicate by touch if it feels appropriate. For example, this could be by holding their hand. Even if they don't respond, they may feel a connection with you and a sense of comfort. Sometimes just being with a person with dementia can be a reassurance.

Tips for non-verbal communication with a person with dementia

- Use physical contact to show you're there for the person. Don't underestimate the reassurance you can give by holding their hand or putting your arm around them, if it feels appropriate.
- Respect their personal space and try to be at eye level. Being too close or standing over them can feel intimidating.

- A person with dementia will read and interpret your body language. Sudden movements, the tone of your voice or a tense facial expression could upset or distress them, even if the words you say are not upsetting. Keep the tone of your voice positive and friendly where possible.
- 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.
- Try to learn to recognise what they are trying to tell you through their body language. For example, if they appear distracted or bored, you could try to change the subject to keep them engaged.
- Visual prompts can be very helpful. They could point to photos, cue cards, language mats, or pictures in magazines or catalogues to express what they want to say. There are also communication apps and websites that show pictures or videos of different objects.
- The person may enjoy drawing or singing to express themselves. Find songs and music from their past that they are likely to be familiar with.

From 'Compassionate Communication with the Memory Impaired'

by Liz Ayres, a Volunteer of the Alzheimer's Association, and former Carer.

DO

Do give short one-sentence explanations

Do allow plenty of time for comprehension – then triple that time!

Do repeat instructions or sentences in exactly the same way (then re-phrase if necessary)

Do eliminate 'but' from your responses and use 'nevertheless' instead.

Do avoid being insistent. Try again later.

Agree or distract them to a different subject / activity.

DON'T

Don't reason.

Don't argue.

Don't confront.

Don't remind them they forgot.

Don't question recent memory.

Don't take it personally.