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# DEMTEC

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## Dementia Toolkit for Effective Communication

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Version for  
family carers

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## 1. Introduction

### 1.1 Who DEMTEC is for and what it tries to do

This toolkit is for people living with dementia, for their family and friends, and for people who meet with them or take care of them.

The effects of dementia can alter the way in which people interact on both sides of a conversation. Poor or damaged skills can lead to people getting the wrong idea about each other and may cause problems or bad feelings between them.

DEMTEC offers practical advice on communicating together.

It does this by pulling together the best advice available from professional experts in the field, and from other carers or people living with dementia, many of whom have contributed to its development.

### 1.2 Dementia and communication

Dementia is caused by a breakdown of the connections in the brain, affecting people's skills, abilities and interactions.

It is an illness that generally gets worse over time. Symptoms include memory loss, difficulty in concentrating and problems with understanding and communicating.

People who are beginning to develop dementia will most often notice problems with their memory and with performing tasks that they used to be able to manage easily.

Problems with memory are a normal feature of ageing, but in people living with dementia they make managing ordinary tasks very difficult and frustrating – or even impossible.

As they struggle to manage everyday tasks, many people living with dementia may try to hide symptoms from loved ones. They may also become anxious, depressed and fearful or irritable. All this can make coping with the underlying condition more difficult.

As the illness progresses these feelings may change or take different forms. People's character and behaviour may also change radically as the result of cognitive loss, which carers often find very difficult to understand or to bear. People living with dementia may feel a sense of loss of identity, begin to garble their words or stop communicating altogether, appearing apathetic and unresponsive.

Nonetheless, though dementia is often sad, undermining abilities and dignity, people living with the illness have a right to be treated with respect.

People around them need to take the time to think through how it might feel to have the illness, and to adopt strategies that help people with their problems, their choices and retaining their dignity.

This should help people living with dementia to keep control of their lives and to minimise their worries. It allows them to keep fighting or to relax, to find humour in their predicament, and to retain a sense of fulfilment and of being valued and loved.

### **1.3 How to use DEMTEC**

DEMTEC contains no technical or overly-complex language – it is intended to be used by, and to be useful to, anyone who needs it.

It doesn't put forward concrete 'rules', but instead it tries to offer ideas and suggestions based on the shared experiences of others.

The toolkit provides strategies to help people keep control of their lives by expressing their choices. It is important to realise that people living with dementia are individuals first and sufferers second.

Even the best suggestions won't always work with everyone – so the best advice of all is to respect people's individuality. Ignore the toolkit's guidance where it isn't helpful for you and be prepared to find ways of managing that suit your own experiences.

What the authors most want is for people living with dementia to be able to communicate more effectively, to have more choices and to enjoy themselves, their friends and the world more as a result. They – and we – deserve it.

## **1.4 How DEMTEC is organised**

There are nine sections, each dealing with an aspect of communication and getting along. Each section offers advice related to that area. The stories section of this website gives examples of the real-life experiences of people living with dementia and their carers, showing how some of the advice might be carried out in different situations.

If you are interested in fuller, more technical versions of the toolkit, these are also available in the Socials Carers and Health & Care Professionals sections of the website. These fuller versions discuss the theoretical background to the toolkit in more depth, and offer advice which is generally more detailed and more specifically aimed at care and health professionals.

The nine sections in the remainder of the toolkit are:

- 2.1 Conversation**
- 2.2 Body language**
- 2.3 Environment**
- 2.4 Reducing anxiety**
- 2.5 Putting yourself in their shoes**
- 2.6 Understanding behaviours**
- 2.7 Helping people keep a sense of themselves**
- 2.8 Checking understanding**
- 2.9 Keeping yourself well**

## 2. Communication Advice

### 2.1 Conversation

Conversation is a process of 'give and take'. It is central to sharing meaning, to helping people keep a sense of themselves and to fully participating in life.

Most people living with dementia engage less in conversation as their illness progresses. This may be a result of problems that the person living with dementia is experiencing (for example their attention may wander). It may also be because others find it difficult to know how to interact with them and tend to limit their conversation to very basic subject matter.

Certain relatively simple strategies can be employed to make conversation more satisfying for both parties.

#### Thinking about approaches to conversation

- Try to think through how it might feel to struggle to communicate if you were living with dementia and think about what might help – and what has helped in the past.
- Conversation **is** caring – you aren't just chatting, you are acknowledging each other as people.
- Communicate naturally where you can but be prepared to lead and re-direct conversation if it is helpful.
- Discussing activities that you or the person living with dementia are engaged in is often a good starting point.
- You can circle around an important point of conversation with someone living with dementia – and find that you get where you want to go eventually.
- Time of day may be important – some people living with dementia find it much easier to communicate first thing in the morning and some at night, for example.
- Try to walk away if you can if you are getting irritable – it helps no one.

## Listening

- Give people your full attention.
- Speak slowly yourself and be prepared to wait for a reply. Let people formulate ideas, which can take time. People living with dementia often say they need to gather their thoughts – and how frustrating it is when they have done so but the discussion moves on before they can say what they wanted to say!
- Take seriously everything that people say to you and if it seems confusing think about what they might mean. For example, if people ask ‘to go home’ it often means that they are feeling worried and anxious.
- Listen for tone of voice – it is an important part of the way we all communicate.
- While it isn’t helpful to mislead people living with dementia, it may sometimes be right to enter into the world that people momentarily believe they are in. Responding as if you are a friend that the person recognises, for example. This is a fine judgement!
- Look for clues in people’s behaviour and try to get a feel for what they might mean.
- We often have an ability to understand one another that isn’t based only on what is being explicitly said, even if we would find it very difficult to explain how.
- Be prepared to be surprised and to learn. Many people who appear to have very limited skills are able to communicate effectively when they are feeling comfortable if they are given time.
- Focus on positives where you can, listening for what people can do rather than what they find difficult.

## Speaking

- Speak slowly – people living with dementia may find it difficult to concentrate through very rapid speech. Use simple words where you can and keep sentences simple – don’t discuss too many ideas at once.
- Think about what you are saying and what has been said to you and be honest in replying unless it is unnecessarily hurtful.
- Deafness or other communication issues may be relevant to your situation. Speak loudly where appropriate and let people see your lips where you can. Using hand gestures is natural and often helps.

- Be prepared to go through what you said several times and be prepared to re-frame questions by putting them in another way – and don't worry if the conversation seems to go somewhere you weren't expecting. Listen anyway, but be prepared to say, 'I'm sorry, I didn't understand what you said'.
- Sometimes pointing to examples or having pictures handy may be helpful.
- Often people with dementia will be trying to explain something in a roundabout way that you may be able to understand after a while. Sometimes, however, it may be impossible to find a shared meaning.
- Find humour where you can. People rarely enjoy being laughed at but often enjoy laughing together.
- It is generally right not to mislead people but always insisting on the truth may be unrealistic, so there is sometimes a case for deflection. For example if someone asks to see their mother it is more appropriate to say something like: 'What were the kinds of things you liked to do with your mother' than 'your mother will be coming soon' because it may lead to disappointment or 'your mother is dead' because it makes people sad without helping much.
- At the end of a discussion, try to make it clear that you have understood and explain what you will do next.

## 2.2 Body language

Important elements of body language include eye contact, facial expressions, hand gestures, touch and body posture.

These aspects of the way we interact can often carry as much information as verbal communication. Even when someone has trouble with verbal communication, they may be able to 'read' these non-verbal signs.

- Be relaxed and don't hurry people – it makes them anxious.
- Smile where you can and offer reassuring physical contact where it is appropriate.
- Make sure people can see your face and that you have engaged their attention.
- Avoid anything that might seem intimidating – sitting on the same level is usually best, for example.



## 2.3 Environment

Communication doesn't occur in a vacuum. Things like background noise or other distracting activities can make communication difficult.

- When you are talking to someone living with dementia they may find it difficult to concentrate, so find a quiet place, with few distractions.
- Turn off the television or radio if appropriate and try to prevent interruptions.
- Think about light, too. Can you both see each other clearly so that you can get visual clues to meaning?
- Keep people in familiar or comfortable surroundings if you can as this will minimise anxiety. Ask people where they will be most comfortable.

## 2.4 Reducing anxiety

Anxiety is a state of excessive concern for an apparently innocent situation. It is common in people living with dementia, particularly in the earlier stages, where it can be the first indication of problems. For a person living with dementia, anxiety may be linked to specific concerns about their condition, such as increasing forgetfulness, or it can be 'free-floating', latching onto other personal concerns. In some cases it may have no obvious triggers at all.

- Pick your moment to talk to people – wait until they are relaxed if you have something complicated to discuss.
- Explain to people what you are doing and why – never start a task with someone without making this clear. Imagine how distressing it would be if someone suddenly started pulling your clothes off with no explanation.
- Don't talk 'over the head' of someone living with dementia even if they seem unresponsive – it often underestimates people's ability to understand and is discourteous and disempowering.
- Speak slowly, use a calm tone and be relaxed and calm yourself. Be patient. Find humour where you can.
- Use reassuring gestures. Holding someone's hand may be helpful.
- Find what relaxes people: gardens, cooking, sharing a cup of tea. Often singing and music can help.
- Allow people their own space when they need it.

## 2.5 Putting yourself in their shoes

It often helps to think of situations you have experienced that share elements with the experience of living with dementia: feeling lost, frightened or not really sure what you were doing, for example, perhaps because you were tired, anxious or in a strange place.

- If you are having trouble understanding someone, think about what you know about them and their character. Do they often talk about their job? Do they often tell people if they are hungry or tired or anxious?
- If people speak in a confused or jumbled way it is often possible to reach for a meaning together. Sometimes you will arrive at a meaning it is clear that neither of you had originally intended!
- Relax as much as you can, and help the person you are talking with to relax.
- Look for clues in people's behaviour and try to feel what they might mean.
- We often have an ability to understand each other that we would find impossible to explain. Accept that sometimes you will get this wrong!
- If you can, find someone else who might be able to help when you feel you cannot understand or help.
- Enjoy your interactions and learn from them.

## 2.6 Understanding behaviours

We communicate in order to get across our ideas and to influence people. Communication with a person living with dementia may break down because of differences between your intentions and their understanding of what you mean. Family members and carers can inadvertently cause agitation or distress when the wrong cues have been picked up or when intentions are unwittingly at odds.

- Try to avoid being judgemental about behaviours that you find difficult. They can be expressions of distress.
- Think about what an unhelpful behaviour might mean. Getting angry may come from frustration, physical discomfort or an unsatisfied need, for example. But bear in mind that although unhelpful behaviour does usually mean something it may not always be possible to interpret and resolve. Trust your intuition.
- Is there an unmet need? Offer some suggestions to try to find out.

- Can you find a useful distraction?
- Be prepared to be treated as someone you are not (for example being mistaken for another relative).
- Be prepared to walk away or to find someone else who may help if you are becoming frustrated yourself. Try not to get angry.

## 2.7 Helping people keep a sense of themselves

People living with the later stages of dementia often begin to lose their sense of identity. Prompts about names and situations are useful reminders.

Making clear what is happening and why helps people to understand what is going on and reduces anxiety. It also provides a environment that may help make an activity easier and more meaningful. Remember also that people change. Allow for this change, and for growth in the individual.

- Always treat people with the respect they deserve. Listen to what they say.
- Let them make choices, even if they are bad ones, providing they aren't overly dangerous. Allow people as much freedom as they can possibly be given.
- Remind people of the real world when necessary, but don't force truth on people for its own sake if it is unnecessary or hurtful.
- Bear in mind what people enjoy doing and help them to do it. Background knowledge about people is naturally very useful – but don't assume people will stay exactly the same forever!
- Find meaningful activities for people. Most people enjoy feeling that they are being helpful and everyone enjoys feeling engaged, interested and taken out of themselves. No one enjoys being bored. Old hobbies may be enjoyed again.
- Memory books (with photos, postcards, newspaper cuttings, etc.) may be helpful aids for starting discussions, which help people to relax and to connect with their lives.
- Allow people to personalise the space around them. Make sure they have access to pictures and objects that are familiar and reassuring.
- Let people be upset if they want – sometimes it is natural. Intuition will tell you when to help.

## 2.8 Checking understanding

This can be particularly important for people living with dementia, who may seem to be speaking 'off subject', or who may be using words that don't seem to fit the context of the conversation.

Taking the time to check that you understand not only makes it easier to get to a person's intentions and meaning. It also shows the person living with dementia that their struggles to communicate are being taken seriously and that a joint effort may help to overcome barriers.

- Work towards a meaning together in discussion if it cannot be found immediately.
- Sometimes it helps to search for clues. Be polite – and enjoy the ride.
- Don't try so hard that you get frustrated yourself. Let go if you cannot find a shared meaning but be prepared to try again.
- Ask if you have understood a meaning correctly.

## 2.9 Keeping yourself well

This is vitally important advice, particularly for family members and other loved ones who may be caring for people living with dementia.

Just as there are a few rare individuals who sail through the experience of living with dementia without apparent anxiety or hardship there are a few carers who find that the whole process comes to them naturally and without worry.

Most of us need help, however.

- Make sure you find some time to relax for yourself if you possibly can – even a break of a few hours a week can make an enormous difference.
- Get advice where you can.
- Talk to friends.
- Don't be afraid to admit to difficulties.