Caring for Someone with Dementia

Communication

National Dementia Helpline 1800 100 500 dementia.org.au

Dementia Australia
Sometimes we are asked, 'Who will I be when I die?' The question is one of existential importance, but it is also distressing. It can be frightening to think about the prospect of death, and this is normal. The question of who we will be after death is challenging, and it is not easy to answer. However, by examining our current selves, we can gain some understanding of our potential selves. This may help us to make decisions about our future and to plan for the future. It may also help us to appreciate the present and to make the most of the time we have left.
Communication

This Help Sheet explains some of the changes in communication that occur as a result of dementia and suggests ways that families and carers can help. It also includes some personal tips on communication written by a person with dementia.

Losing the ability to communicate can be one of the most frustrating and difficult problems for people living with dementia, their families and carers. As the illness progresses, a person with dementia experiences a gradual lessening of their ability to communicate. They find it more and more difficult to express themselves clearly and to understand what others say.

Some changes in communication

Each person with dementia is unique and difficulties in communicating thoughts and feelings are very individual. There are many causes of dementia, each affecting the brain in different ways.

Some changes you might notice include:
- Difficulty in finding a word. A related word might be given instead of one they cannot remember
- They may speak fluently, but not make sense
- They may not be able to understand what you are saying or only be able to grasp part of it
- Writing and reading skills may also deteriorate
- They may lose the normal social conventions of conversations and interrupt or ignore a speaker, or fail to respond when spoken to
- They may have difficulty expressing emotions appropriately

Where to begin

It is important to check that hearing and eyesight are not impaired. Glasses or a hearing aid may help some people. Check that hearing aids are functioning correctly and glasses are cleaned regularly.

Keep in mind

When cognitive abilities such as the ability to reason and think logically deteriorate, the person with dementia is likely to communicate at a feeling level.

Remember

Communication relating to feelings and attitudes is made up of three parts:
- 55% is body language which is the message we give out by our facial expression, posture and gestures
- 38% is the tone and pitch of our voice
- 7% is the words we use

These statistics* highlight the importance of how families and carers present themselves to a person with dementia. Negative body language such as sighs and raised eyebrows can easily be picked up.


What to try

Caring attitude

People retain their feelings and emotions even though they may not understand what is being said, so it is important to always maintain their dignity and self esteem. Be flexible and always allow plenty of time for a response. Where appropriate, use touch to keep the person’s attention and to communicate feelings of warmth and affection.

Ways of talking

- Remain calm and talk in a gentle, matter of fact way
- Keep sentences short and simple, focusing on one idea at a time
- Always allow plenty of time for what you have said to be understood
- It can be helpful to use orienting names whenever you can, such as “Your son Jack”

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Body language
You may need to use hand gestures and facial expressions to make yourself understood. Pointing or demonstrating can help. Touching and holding their hand may help keep their attention and show that you care. A warm smile and shared laughter can often communicate more than words can.

The right environment
- Try to avoid competing noises such as TV or radio
- If you stay still while talking you will be easier to follow, especially if you stay in the person’s line of vision
- Maintain regular routines to help minimise confusion and assist communication
- It is much less confusing if everyone uses the same approach. Repeating the message in exactly the same way is important for all the family and all carers

What NOT to do
- Don’t argue. It will only make the situation worse
- Don’t order the person around
- Don’t tell them what they can’t do. Instead suggest what the person can do
- Don’t be condescending. A condescending tone of voice can be picked up, even if the words are not understood
- Don’t ask a lot of direct questions that rely on a good memory
- Don’t talk about people in front of them as if they are not there

Adapted from Understanding difficult behaviours, by Anne Robinson, Beth Spencer and Laurie White 1989. Eastern Michigan University, Ypsilanti, Michigan.

Tips from a person with dementia
Christine Bryden (Boden) was diagnosed with dementia at age 46, and has shared a number of her insights about ways that families and friends can help a person with dementia. Christine is also the author of a number of publications, including Who will I be when I die?, the first book written by an Australian with dementia.

Christine provides these tips for communicating with a person with dementia:
- Give us time to speak, wait for us to search around that untidy heap on the floor of the brain for the word we want to use. Try not to finish our sentences. Just listen, and don’t let us feel embarrassed if we lose the thread of what we say
- Don’t rush us into something because we can’t think or speak fast enough to let you know whether we agree. Try to give us time to respond – to let you know whether we really want to do it
- When you want to talk to us, think of some way to do this without questions that can alarm us or make us feel uncomfortable. If we have forgotten something special that happened recently, don’t assume it wasn’t special for us too. Just give us a gentle prompt – we may just be momentarily blank
- Don’t try too hard though to help us remember something that just happened. If it never registered we are never going to be able to recall it
- Avoid background noise if you can. If the TV is on, mute it first
- If children are underfoot remember we will get tired very easily and find it very hard to concentrate on talking and listening as well. Maybe one child at a time and without background noise would be best
- Maybe ear plugs for a visit to shopping centres, or other noisy places

FURTHER INFORMATION
Dementia Australia offers support, information, education and counselling. Contact the National Dementia Helpline on 1800 100 500, or visit our website at dementia.org.au

For language assistance phone the Translating and Interpreting Service on 131 450