

Communicating well

5 Communication in the later stages of dementia

Key messages

- It is possible to communicate with a person with advanced dementia.
- How we communicate with a person with advanced dementia can vary, depending on what we know about the individual – particularly things they have enjoyed during their life.
- Communication remains important throughout a person's journey with dementia.

Is it possible to communicate with a person with advanced dementia who may not be able to talk and appears unresponsive? When you first meet someone with no language and apparently little of their personality remaining, it is easy to believe that it is not.

But there is clear evidence – through the power of music, song and touch – that people with advanced dementia do not lose the ability to communicate.

Naomi Feil, founder of Validation Therapy, shares a breakthrough moment on film with Gladys Wilson, 87, who is virtually unable to speak. As Naomi starts singing gospel songs – favourites of Gladys, who has Alzheimer's disease – Gladys starts tapping to the songs and begins to sing along with her.

Naomi says: 'When she moved I moved with her. I matched the intensity of my voice to the intensity of her movement. And pretty soon, for a split second, we became one person.'

You can watch the remarkable transformation in Gladys in an extract from the film, 'There is a bridge', which you can view [here](#).

Those of us who have cared for someone with advanced dementia over a period of time know that there is more to good dementia care at this stage than just keeping the body alive. The person usually has little or no speech, can no longer move independently and may have lost the ability to maintain their body posture at all. But what we learn is that people are people throughout this process.

Back to basics

How we communicate with a person with advanced dementia can vary, depending on what we know about the individual – particularly things they have enjoyed during their life. It can

be influenced by where they are receiving the care (in their own home, care home or hospital) and the relationship they have with the people providing care and support.

It sometimes helps to think about how we communicate with a baby or toddler just starting out on their life. We have to be very careful when making comparisons between older people and children. We do not want to be in the habit of treating adult citizens as if they were children in a way that would feel patronising.

From a conceptual point of view, however, if we see human development as being triggered by the brain maturing through infancy and childhood, what we see happening in dementia can be viewed as a reversal of this process.

There are some striking similarities between what babies and toddlers need from their carers or care workers and what people with advanced or end stage dementia need from theirs. Most people who have cared for babies or toddlers find some reactions that come quite naturally.

We feel drawn to use touch, to hold, to stroke gently, to achieve eye-contact, to try to make them smile, to soothe them when they cry and to make sure they are comfortable. Over time we get to know the personality of the baby or toddler and what they are trying to communicate.

Communicating with a person with advanced dementia requires us to use these same set of skills. We need to recognise that we are caring for someone who has a long life behind them and many stored memories and experiences. If we can find a bridge into these memories we can find a way to communicate with them and nurture their spirit at this final stage of life.

Keep communicating

Communication should be there until the end. Never assume that the person cannot hear or understand you. Try reminiscing about their past, talk to them about things of interest (for example, how the family are and what the grandchildren are doing). Pick up on a hobby or interest they may have had (if they enjoyed horse racing, talk about the races that day, the form of the horses, the odds and the jockeys involved).

Non-verbal communication is vital. Touch can be used to stimulate senses and provide reassurance. Try to achieve eye contact. Be aware of the tone of your voice. Remember that the expression on your face will convey more than the content of your words.

Communicating well with a person in end-stage dementia is not written about extensively. It is something that is best seen first-hand. Some years ago, communication experts Kate Allan and John Killick undertook an in-depth piece of work in Australia called the Good Sunset Project specifically to develop ways of working with people with advanced dementia. They based this on a communication approach developed in coma work and got some very positive results (see Further reading and resources below).

Making connections

When a person is at the end stage of dementia it may appear that they have completely withdrawn from our world and communication is difficult. At this stage it is worth considering alternative forms of stimulation to make a connection.

Smell

The sense of smell is very powerful. Scents and smells can create a link and bring back reassuring memories of times gone by (for example, the aroma of baked bread or a favourite perfume or flowers). Having these close by can produce a reaction and a connection.

Touch

Holding hands, stroking a person's face or arms, or brushing their hair can be soothing and be pivotal in making a connection. A woman may like the feel of a silk scarf on her neck.

Vision

A family photograph or a picture of a favourite view can produce a reaction – perhaps encouraging the person to open their eyes and reach out.

Music

Playing or humming favourite tunes can bring back happy memories. Someone who lived in the countryside may react to bird song. If they lived by the coast, sounds of waves crashing on the shore may lift their spirits. Music can lead to finger or foot tapping, a smile, perhaps a tear.

Singing

Often people with dementia who stopped speaking a long time ago can sing along to a familiar tune, remembering the words.

Dancing and movement

Depending on their mobility, the person with dementia may connect though dancing. Perhaps they will get up and move around or put their arms in a familiar dance hold or move their feet to the rhythm of the music.

Art

Connections can be made through art by the simple sensory act of holding a brush or pencil and scribbling, painting or drawing on paper. (See 'Creative arts' in the 'Keeping active and occupied' section).

Further reading and resources

Alzheimer's Society (2012) '**The later stages of dementia**'. Factsheet 417. London: Alzheimer's Society.

Alzheimer Scotland (2005) '**Letting go without giving up – understanding behaviour**'. Edinburgh: Alzheimer Scotland.

Killick, J. and Allan, K. (2005) 'Good Sunset Project: quality of life in advanced dementia', *Journal of Dementia Care*, vol 13, no 6, pp 22–23.

Killick, J. and Allan, K. (2006) 'Making contact with those close to death', *Journal of Dementia Care*, vol 14, no 1, pp 22–24.

Killick, J. and Allan, K. (2006) 'The Getting Through Initiative: inside the interactions', *Journal of Dementia Care*, vol 14, no 2, pp 27–29.

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