**COMMUNICATING**
with people with dementia around end-of-life

### Why do we communicate?

To be human is to communicate. It is at the heart of our relationships. Communication and relationship are also the key to good care, to person-centredness and to good practice.

People with dementia are no different. Like other people, people with dementia need to communicate with a range of people on a daily basis, including their relatives, healthcare staff, GPs and others. Poor communication with people with dementia in residential care can put them at risk of unnecessary suffering. Poor communication can also mean that people with dementia are deprived of choice, control, and even respect. Communication is key to identifying and meeting needs.

Communicating with people with dementia can be challenging, as their condition may make it difficult for them to concentrate, their language skills may vary from day to day, they may struggle to remember what has been said, they can find it difficult to make sense of metaphors, idiom, abstraction, and they may also suffer from other age-related communication difficulties such as loss of hearing. So, the sorts of things that we normally rely on to make our communication effective (see box above) may not always work when we are communicating with someone with dementia.

### TRUTH-TELLING OR COLUDING?

Should a person with dementia, who has significant short-term memory loss, be ‘corrected’ when they forget distressing news (for example, if they go looking for a long-dead loved one)?

**No lie is needed if the response is to the emotions rather than the facts.**

For example, distressed woman with dementia says to staff member “I’m looking for Mikey [dead husband]… Have you seen him?” Staff member replies to the emotional content “I’m not sure. You look a little troubled, shall I walk with you?”

(from Laura Green blog - http://linkis.com/wp.me/Q7zmC)

### WHAT MAKES FOR GOOD COMMUNICATION?

- Being able to see & hear the other person
- When both parties respect each other
- Good listening / minimal distraction
- When it’s two-way, rather than one-way
- Using the right words/a clear message
- Message sent/received at a good time

### “Not knowing where I am doesn’t mean I don’t know what I like.”

- Cesare Pavese
“They may not remember what you say, but they will remember how you made them feel.”

TIPS FOR COMMUNICATING WITH PEOPLE WITH DEMENTIA

- Try not to enter their world full of anxiety and busyness. Regardless of what you say, how you are will affect them. If you can, calm yourself down before entering ‘their world’.
- Get their attention by making eye contact with them. Make sure they can see and hear you easily.
- Speak clearly and calmly and at a slightly slower pace.
- Avoid speaking sharply or raising your voice, as this may distress the person.
- Use short, simple sentences. If you need to ask them something, express one idea at a time. Giving people choice is important but presenting too many options can be confusing and frustrating. Use simple yes/no questions (“would you like to wear this?”) and avoid asking double-ended questions (“would you like to wear this or will this make you too warm today?”).
- Show respect. Don’t talk to the person as you would to a young child.
- Try to laugh together about the inevitable misunderstandings and mistakes – it can help.
- Try to include the person in conversations with others. Being included can reduce feelings of exclusion and isolation.
- If the person doesn’t understand what you are saying, try
  - breaking it down into smaller parts
  - using words or pictures or objects to help them understand you and express themselves.
- If the person says something you know to be incorrect, try not to contradict them directly or ‘correct’ them. Instead, try to see behind the content to the feelings or meaning that they are expressing.
- If the person has a difficulty finding a word for something, ask them to explain it in a different way. For example, if they can’t remember the word ‘watch’, they might offer ‘arm clock’.
- Pay close attention to their body language – they may be “speaking volumes” by their facial expression, by the way they are holding themselves or sitting, or by repetitive movement. In a way, all of their behaviour could be communicating something.
- If they are feeling low or sad, don’t try to “jolly them out of it” – often, the most respectful way to respond is just notice and acknowledge that they seem to be down, and to just be with them in their sadness, empathising rather than ‘fixing’.

LISTEN, TALK, CONNECT

Understand that this disease is, in many ways, like all others. Trying to reason with the symptoms (‘argue’ with the person) will not work.

Don’t be afraid of silence. Just being with the person may bring great comfort (to them and to you).

Help the person to be happy in the time that they are living in. Follow them, go with their mood and don’t try too hard to change it. If they are describing their wedding day, ask them more about that special moment.

If you only see the person occasionally, try to avoid saying or “you remember me, don’t you?”. This is often our first reaction, based on our need for reassurance. Instead, make it easy for them by telling them your name and asking simple questions to understand where they are at that moment.

Adapted from Care UK