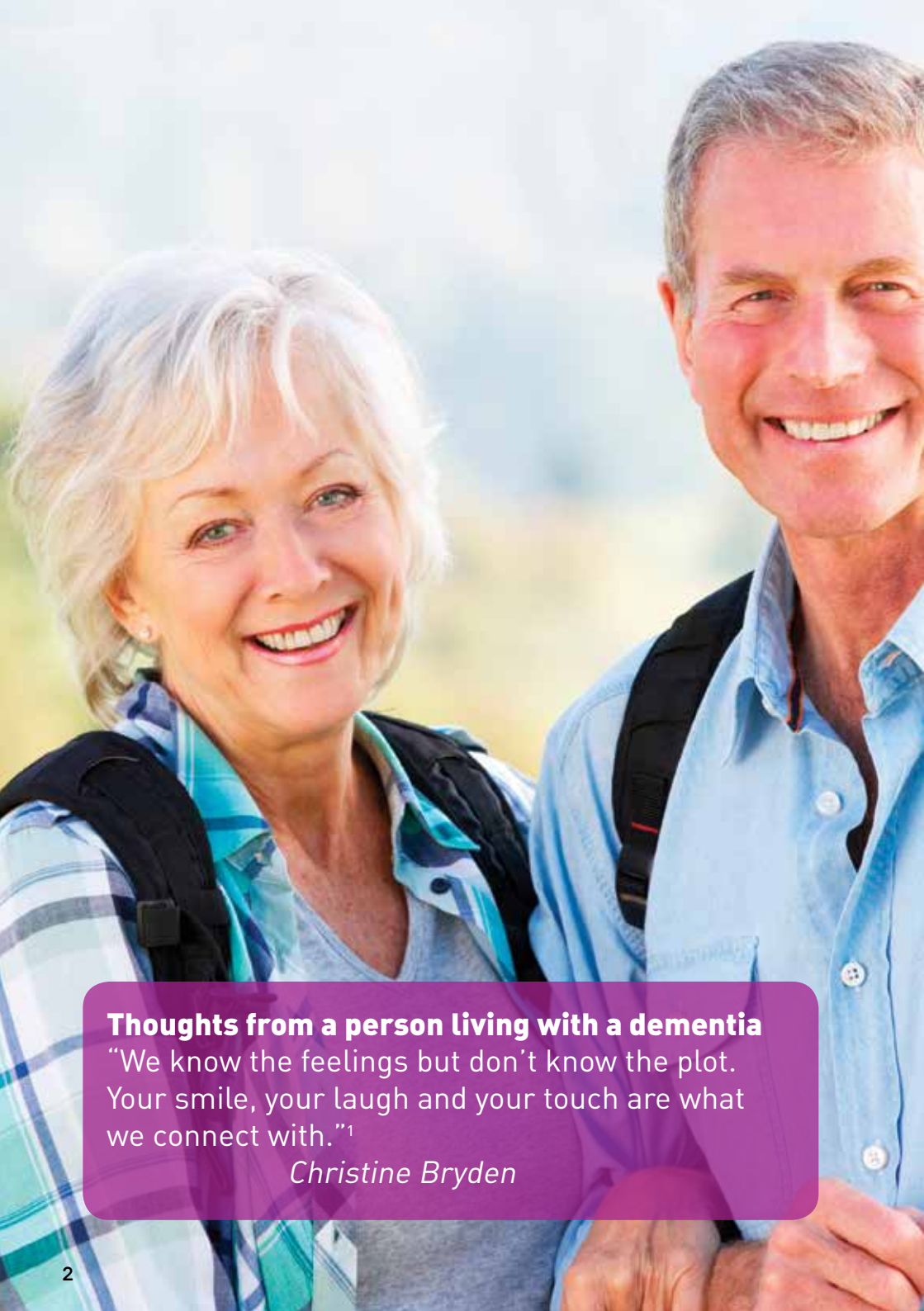


Communicating effectively with a person living with a dementia





Thoughts from a person living with a dementia

“We know the feelings but don’t know the plot. Your smile, your laugh and your touch are what we connect with.”¹

Christine Bryden



Why is communication important?

When a person is living with a dementia it is likely that their ability to communicate will be affected in some way. This will depend on the area of brain that is damaged and/or the stage of the person's progression through their illness.

The person cannot change the way that they communicate with us. It is our responsibility to change how we communicate to enhance their understanding and wellbeing.

This booklet aims to provide you with a general overview of the potential communication difficulties a person living with a dementia may experience, including:

- memory loss;
- difficulty forming ideas;
- difficulty understanding;
- difficulty with verbal expression.

Not everyone with dementia will experience all of these.

It also offers guidance on how you can communicate more effectively with a person living with a dementia and understand the feelings the person is experiencing.

Memory loss

Memory loss or poor short-term memory can cause a person living with a dementia to:

- have difficulty remembering what has been said to them;
- drift from the point or topic of conversation;
- be repetitive, ask the same question, tell the same story or give the same piece of information a number of times;
- talk about the past a lot;
- experience difficulty thinking of names of people, places and objects;
- start to say something and forget what they are talking about.

Thoughts from a person living with a dementia

“Empathy heals...just love us as we are.”¹

Christine Bryden

Helpful hints

- Say the person's name to gain attention at the start of the conversation and throughout.
- Try to sit at the same level as the person with a dementia.
- Repeat yourself if you are unsure the person with dementia has heard or understood you.
- When more than one person is present try to have only one person speak at a time.
- Write down key words to support what you have said (if the person's ability to read is intact).
- Introduce the topic and 'set the scene' for the person, eg “I'd like to talk about your brother John”.
- Gently remind the person of what they or you were saying, eg “you were just telling me”.

Christine Bryden

Ideas to help memory

In the earlier stages of a person's dementia there are some things that you can do to help their memory:

- encourage the use of written notes, eg a calendar or notice board;
- use clocks and timers to set reminders for the person with dementia;
- place written labels and picture labels on doors and drawers to remind the person of the contents;
- keep a diary of daily events and for visitors to make notes of their visit;
- keep pen and paper by the phone;
- consider daily rehearsal of important information;
- prioritise what needs to be remembered;
- keep the person with dementia involved in decisions and try to avoid taking over.



Thoughts from a relative of a person who lived with a dementia

“When the person with dementia is talking and their conversation goes from one thing to another, the person with them should just go with it, no matter if it makes sense or not.”

Help with forming ideas

We use thoughts and ideas we form in our mind to influence what we are going to say. A person with a dementia may experience difficulty forming ideas and thoughts or appreciating and understanding the ideas of others. This can mean the person may experience difficulty:

- being able to think of what to say, which will make it difficult for them to start a conversation;
- understanding what is said to them resulting in difficulty following instructions;
- being able to join in or follow a conversation with others;
- being able to answer questions appropriately.

Helpful hints

- Pause and allow time for the person with a dementia to process what you have said or asked and to formulate a response.
 - Use gestures and nonverbal cues such as pointing or using pictures to aid understanding of what you are saying.
 - Repeat yourself if you are unsure the person with a dementia has heard or understood what you have said.
 - Minimise distractions and noise levels.
 - Write down key words that you are saying and/or show pictures to encourage understanding.
 - If the person with dementia loses focus then gently remind them of the topic, eg “I would like to talk to you about your necklace”.

Thoughts from a relative of a person who lived with a dementia

“I remember with daddy using the ‘ping pong’ effect, I think it’s called. If he said something was ‘brilliant’, I said ‘brilliant’ and then he said it; it went back and forth a good few times.”

Help with understanding

The person with a dementia's ability to understand, process and respond to information heard, and the speed at which they do so can be affected by their condition. This can cause them to experience difficulty with:

- being able to join in with what is going on or follow a conversation with others;
- understanding or remembering what is said to them;
- being able to answer questions appropriately;
- following television programmes or radio.

Helpful hints

- Speak slowly and clearly and at a normal volume.
- Keep your language short and simple.
- Repeat if you are unsure the person has heard or understood what you have said.
- Change the way you say something if you are unsure that the person has understood, despite repetition.
- Emphasise key words.
- Pause and allow time for the person to process what you have said.
- Use gestures and non-verbal communication to aid understanding of what you are saying.
- When more than one person is present, try to have only one person speaking at a time.
- Use pictures and written words to aid understanding (if the person's ability to read and recognise pictures is intact).
- Avoid sayings like 'tie the knot' - say 'getting married' instead.
- Introduce the topic and 'set the scene' for the person eg "I'd like to talk about your sister Rose".

Thoughts from a relative of a person who lived with a dementia

"Having a topic to fall back on, like with daddy and the wedding, or Easkey and fishing. I found having topics to focus on were so helpful when he was struggling to find words, as they were familiar and started him off on a conversation he could find the words for."

Help with verbal expression

A person with a dementia may have difficulty organising and expressing ideas required for talking. Starting conversations and keeping to the topic can also be impaired as the person may experience difficulty forming ideas and concentrating.

The ability to speak clearly may be impacted by speech that may sound 'confused'. Difficulties with engaging in conversation can include:

- jumbled speech;
- use of the 'wrong' word, eg saying 'kitchen' when you mean 'bathroom';
- struggling to find the right word;
- hesitations and repetitions;
- going off on a tangent/losing focus on the topic;
- speech slurred/sounding less clear;
- joining in with what is going on or following what others are saying;
- being able to answer questions appropriately;
- thinking of names of people, places or objects;
- being able to think of anything to say.



Helpful hints

- Avoid asking questions, where possible - these put pressure on the person to respond. Try offering up suggestions instead, eg "how about a cup of tea" and "let's take a walk".
- When the person with a dementia has difficulty finding the right word offer up suggestions, but avoid finishing the person's sentence for them.
- When the person with a dementia cannot express themselves clearly, watch their nonverbal communication (body language, facial expressions) closely to give you a clue.
- Encourage all forms of communication, gestures, facial expressions, pictures etc.
- If you have not understood what the person with a dementia has said you can ask them to repeat. Avoid asking this too often so as not to upset them.

Helpful phrases

- You seem worried/anxious.
- I can never remember either.
- You seem to miss your..
- It can be hard to think of things.
- Let's do this together.
- I really need your help.
- I'm feeling lonely and lost too.
- I could do with a friend too.
- Isn't it frustrating when you can't think of the word?
- Is it something to do with...?
- You loved living in....

Non- verbal communication

Non-verbal cues make up around 93% of how we communicate with each other. They can give us more insight into what the person living with a dementia is trying to say, especially at times when verbal communication is difficult. Despite all the difficulties with language that can be experienced non-verbal communication often remains intact. Therefore pay close attention to all non-verbal cues such as facial expression, gesturing, pointing etc. as they can help us understand what the person with dementia is communicating.

Yes/no

It is important to note that a person living with a dementia may mix up their yes/no response. The person may say 'no' when they mean 'yes' and vice versa. Therefore, as advised, please pay close attention to what their non-verbal cues are telling you.

Understanding feelings

A person with a dementia will continue to experience the same feelings as you and I. However changes in cognitive function, along with increasing difficulties with communication can mean that the individual struggles to communicate these feelings in the way that they would have done. For this reason, differences in their communication and/ or their behaviour can be an indication of a need or feeling that the person is trying to express.

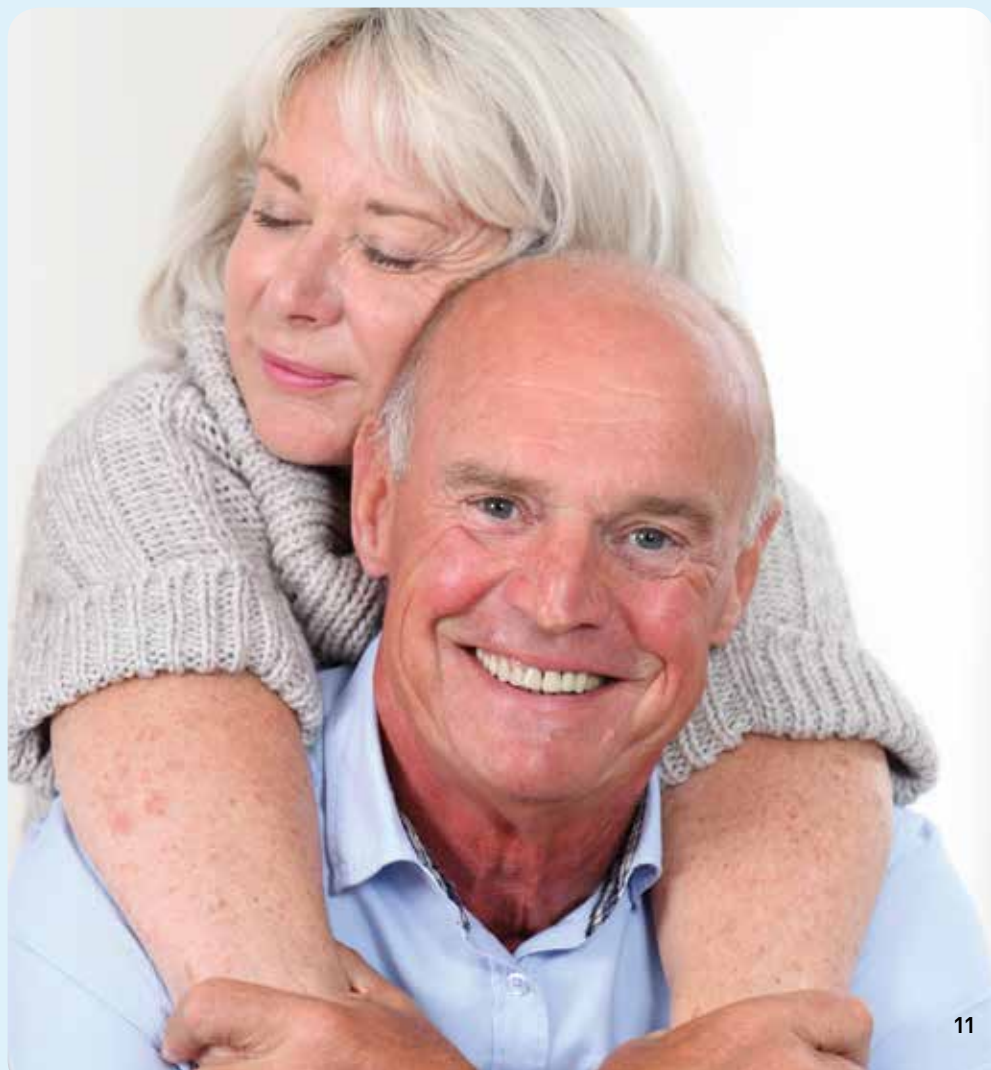
As the person continues on their journey through dementia, the ability to control their speech and or behaviours will be further affected. Therefore we need to be aware of how we are communicating with the person and how our responses can impact upon how the person is feeling and behaving. The person living with a dementia will not be able to adjust or change the way in which they express themselves.

It is our responsibility to change how we communicate in order to effectively support the person. We must STOP, LOOK and LISTEN and search for the meaning behind every communication / or behaviour, especially if the person is anxious or distressed.

It is important that we look beyond the person's actual words or actions and search for the underlying feeling being communicated and respond effectively.

If the person with dementia says for example, 'I want my mum' or 'I want to go home' they may be communicating the need for security and love. Talk to the person about their mum/ home life for example, 'I'm sure you miss your mum'. The person may be feeling lost and insecure. Reassure them and try to promote feelings of safety. Ignoring or diverting the person does not address the underlying feelings being expressed. Once you have addressed the feelings, it may be helpful to try and divert the person's attention by starting up an activity, a different task or offering a cup of tea where appropriate.

It is important that we take time to try and understand the feelings and experience of the person living with a dementia in order to enhance their quality of life and sense of wellbeing.





Phrases to avoid

- You've just asked me that
- You don't go to work anymore.
- Your mum died a long time ago.
- Can't you think of something to do.
- You've forgotten again.
- I've already told you.
- Wait a minute.
- Stop doing that.

Other areas that may affect communication

Reading and writing

The ability to read can be impaired when a person is experiencing a dementia. Reading can become difficult as the person may be unable to remember what they have read, understand the words or concentrate long enough. There are times when the person may only understand short, simple written phrases or single words.

Writing may also be affected as they may no longer be able to hold and use a pen, and transfer their ideas into written words.

If the person with a dementia appears to be struggling with reading and or writing, and appears upset or frustrated by this, gently reassure them and do not ask them to read or write for you.

Use picture and photograph books and books with larger print.

When English is not the first language

There may be times when the person living with a dementia does not speak English as their first language. If they are talking in another language, or switching between English and another language it would be helpful to arrange for an interpreter to visit. The interpreter can give insight into the person's language abilities, and provide helpful phrases to aid effective communication.

When there is significant hearing impairment

If significant hearing loss is affecting the person's ability to communicate with others, you should consider referral to the sensory impairment team.

Useful contacts

Alzheimer's Society

Unit 4
Balmoral Business Park
Boucher Crescent
Belfast
BT12 6HU
Tel: 028 9038 7770
www.alzheimers.org.uk

Northern Ireland Health and Social Care Interpreting Service

First floor – Graham House
Knockbracken Healthcare Park
Saintfield Road
Belfast BT8 8BH
028 90563794

Age NI

www.ageuk.org.uk/northern-ireland

The Dementia Services Development Centre

The Mount Business & Conference
Centre
2 Woodstock Link
Belfast
BT6 8DD
Northern Ireland
Email: dementiacentreni@stir.ac.uk
Tel: 028 9073 0160 or
01786467740

Lead author Ruth Sedgewick, Belfast Health and Social Care Trust.
January 2014.

References

1. Bryden C. *Dancing with Dementia: My Story of Living Positively with Dementia*. London: Jessica Kingsley Publishers;2005

Bibliography

Alzheimer's Society UK. Communicating [online]. Available from: http://www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=130 [Last accessed 20 August 2014]

Barnes CJ. *Chatter Matters. A presentation for Carers of People with Communication and Memory Difficulties*. Published by the Author. 2003.

Powel J. *Care to Communicate. Helping the Older Person with Dementia*. London: Hawker Publications;2000.

Acknowledgements

Some information adapted from
Dementia Care Matters,
St George's House,
34-36 St George's Road,
Brighton, BN2 1ED.
Tel: 01273 242335.
Web: www.dementiacarematters.com
Email: info@dementiacarematters.com



Public Health Agency, 12–22 Linenhall Street, Belfast BT2 8BS.
Tel: 0300 555 0114 (local rate).

www.publichealth.hscni.net