BEYOND WORDS

Communicating with loved ones living with dementia when words are not enough – tips from partners and relatives, professional staff and academics.

‘Beyond Words’ – when we say we love someone beyond words, it is often the look in our eyes, the tone of our voice, even our gestures, that express our love.

This booklet is about communicating with the person you care for when words are no longer enough.

‘There is a story here of growth in the midst of decline, my mother changing – and I with and in relation to her’

Elinor Fuchs, writer

Dementia takes many different forms for different people. How our loved ones with dementia change over time is unpredictable – changes can be gradual or sudden. People’s mood, and with it their wish or ability to communicate, can vary from one moment to the next.

We all want to stay in touch with our loved ones if and when they find talking too difficult – or we find their words don’t make much sense any more. This booklet offers some very simple techniques to help you communicate with them as intimately and eloquently as you once did.

Our ideas and stories are relevant for any stage of the illness the person has reached. So it may be helpful for you to try out some of the techniques while the person is still happy to engage in ordinary conversation.

‘my mission was to make clear to people that there was a considerable level of intelligence at work behind the incoherence’

Philip

Example One

I try clapping her hands inside mine,
and she picks up on the game.

Or it becomes a game because she picks up on it.

She keeps perfect time, and mostly
gets the pattern just right.

Clap! Cross right.
Clap! Cross left.
Clap! Clap Clap!

Mother is eighty-four with advanced dementia,
I am in my fifties and we are playing patty-cake.

We are doing childhood all over again.

For all I know we are doing it for the first time.

We are having such a good time.

Adapting to the changes

‘For most people, this set of circumstances – caring for someone with dementia –happens only once. So there is no easy way to draw on your past experience, nor a chance to learn and reflect on everything you need to as you go along. That’s why listening to, and sharing with, other people is so important’
Geoff & Janet

We often talk about what our loved one can no longer do or has forgotten – it becomes a list, a language, of losses. The losses are ours, actually, even more than for the person with dementia. Our feelings of loss are tied up with what we used to do together, how we used to be with each other in public and in private, before he or she became ill.

What we often miss most is the kind of conversations we used to have, the lively gossip, the serious discussions, the jokes and that sense of a shared life full of meaning and memories that we used not even to have to mention for it to be part of our world. How can we conserve what is still positive and possible and alive in our relationship with our loved one who is ill?

‘I am a words person – it’s particularly hard to suspend one’s instinctive search for clarity in a conversation’

Helen

Our whole constellation of other relationships changes too; it may become difficult to spend relaxed time with family and friends, for example. But these relationships often become deeper, not less, over time.

‘Dementia is a progressive condition so communication with the person changes and you have to adapt’

Professional care worker

Looks, Touch, Tone of Voice

Our society places a high value on verbal fluency. But this is not the only – nor the first – medium through which we communicate with each other. Think about the ways, from when we were very young, we learnt how to:

- Tune into how the other person is feeling – a musical metaphor as well as the reality that music is a way to connect
- Go with the flow, be in the zone
- Improvise and play: for example, with finger games, sing-songing', pretence, peek-a-boo, blowing bubbles with a tub and wand, moulding clay or play doh, playing simple musical instruments, creating tiny surprises
- Enjoy creating mutual attentiveness, for example by taking turns in a conversation
- Make up word games, in which language has no purpose except enjoyable exchange and where meaning is created in the moment, as if by magical accident

> 'the memory of words he had loved long ago still delicately chimed'
>
> **Nicci Gerrard, writer**

‘we tried not to base our expectations of our next meeting with our sister-in-law on yesterday’s experience with her, whether it was good or difficult – today could be totally different’

Geoff & Janet

- ‘Play catch’ with nonsense words as part of the to-and-fro
- Mirror the other person’s body language – dance with your hands
- Mime what you want or what you want the other person to do
- Create little rituals of greeting and farewell: like a particular way of saying hello, or a handshake, playful goodbye wave
- Use facial expressions, gestures and tone of voice to communicate – ‘it’s not what you say, it’s the way that you say it’
- Embrace the absurd...

‘I talk as if we are having a conversation about common interests. He listens, sometimes looking puzzled, at other times seeming to be interested; now and then he will smile if I say something funny’

Gabriel

‘laughter is both the medium and the goal of such games – a merriment that the other can catch without ever knowing its cause’

Liz Barry, researcher

As adults, we do most of these things intuitively – they have become second nature in our daily interactions, and we often only become conscious of their value when we’re around young children.

Now, with the person who may be finding words more difficult – whether speaking their own words or understanding yours – you can consciously develop your capacity to convey the vital value of their presence, their personality, in your life. As psychologists have known for many years, play is a way of reaching and nurturing the authentic, creative dimension of a person’s personality – all the more important when that person has few external goals or expectations in their life.

‘Holding his hand, an arm round the shoulder for a cuddle calms him better than talking... Just try to keep the person happy’

Jan

Example Two

Almost daily on the telephone we have our weird little chats, our excursions into zero-degree speech, speech without intention or result.

"Hello, Mother," I begin. And mother lobs back enthusiastically.

"Hello, my mother, duther, wrubber, brother, dear, dear, lovely, dovey --"

[Then her mother says:]

"There was a lot of starting at the beginning."

Starting at the beginning?

"Oh, this is marvellous!"

I chuckle. Mother always laughs when she hears a laugh, and we hang up laughing.

‘I have learned to try and connect emotionally with my dad rather than purely cognitively. This involves keeping eye contact, being patient and smiling, to see the person inside, rather than the disease’

Ashley

Just like you, the person with dementia has a repertoire of remembered phrases, gestures and facial expressions that are characteristically and recognisably their own. Just like you, they will pick up quickly on non-verbal cues, like your frown or your smile or the irritation or enjoyment in your voice.

The identity of each person persists in their distinct way of talking, walking, eating, the kind of shape they make in the world. So it is important to give these forms of emotional and sensory expression the central role they deserve – they may in time become the only way the person with dementia can sustain a relationship with you.

And such ways of connecting make the communication between the two of you warmer and more equal, more open to shared pleasure, which is its own purpose.

It helps to think of these activities as a performance, an improvisation in the now that celebrates what humans can do, with and without language, to stay in touch with themselves and each other. Words may still form part of the interaction, but more for their tone and pitch and sonic qualities (rhythm, rhyme, alliteration), their melody.

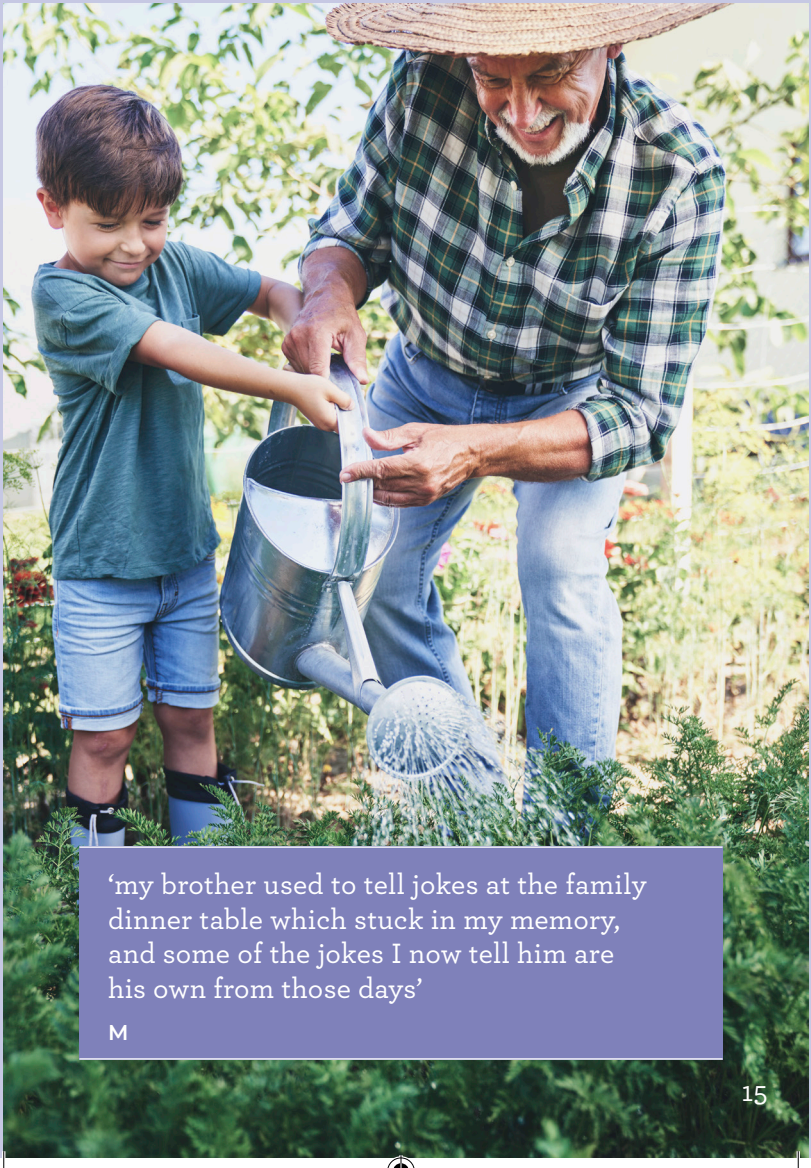
‘I would sometimes touch his hand, for reassurance, for being alongside even when the words were failing us both; over time, we resorted more and more to simple eye contact and physical touch – giving up on the struggle to do it with words’

Philip

Good communication is about co-creating the ‘we-here-now’, the awareness of the moment in its value and its possibilities. Shared conversation or activity -- with words or without -- should not be about ‘getting something done’. It is not a transaction, it does not have to get somewhere. It lasts as long as it lasts.

‘conversation in those living with dementia can be seen as the purest use of the body in speech. Lil’s language is a sensory production, in every sense; it is embodied, full of sound, pace and energy of delivery. Her language is, as it is identified in her daughter’s memoir, a “shimmy”, a dance’

Liz Barry, researcher



‘my brother used to tell jokes at the family dinner table which stuck in my memory, and some of the jokes I now tell him are his own from those days’

M

Example Three

[In the photograph] my left hand is clasping Cath's. . . . We are laughing. Cath's eyes are closed, with, I guess, the intensity of the feeling.

It is a shared joke – one of many – but since she uses little language it may be something we have both noticed and looked at.

Or it may have been that one of us has thought of something and merriment has spilled over onto the other.

As always there is a complicity that goes beyond words.

Some Dos and Don'ts

These may be especially useful if you're visiting or haven't seen the person for a while.

Do:

- Greet the person with a smile, and make friendly eye contact – show you're pleased to see them
- Take a while just to sit and let them get used to your presence; give them your full attention
- Listen, without judgement, to the shape as well as the content of what they are saying; and be patient – it may be easier to understand their facial expression and tone of voice than their words
- Use a soft voice and speak clearly
- Match your tone of voice and facial expression to what you're saying

'I have made photobooks of past happy memories and my husband really enjoys them with others and on his own'
Jan

‘find out what you can about the person’s interests when they were young and mirror it back to them, but without asking them difficult questions about it’
Gabriel

- Keep your side of the conversation light-hearted and straightforward
- Remember that life can be very tiring for someone who has dementia
- Be open to surprises about what they can do or remember that you assumed no longer possible
- Buy a sensory or fidget toy (search for ‘sensory products for dementia’) and show them ways to play with it – as a kind of third thing you can focus on together and enjoy
- Make yourself more informed about dementia, for example by reading books and articles and/or taking a short training course – of which there are many, in person and online

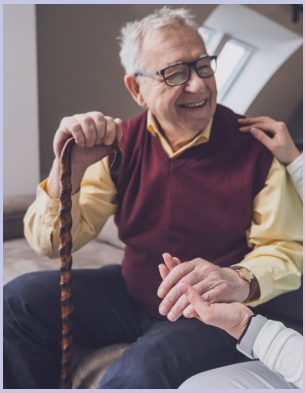
‘what a great thing live music is, handling instruments or dancing!”
Sue G

‘I use pictures and objects when I’m trying to explain something or asking them a question’
Professional care worker

Don’t:

- Lean over them too closely or invade their personal space
- Stare at them OR refuse to meet their gaze
- Shout, use a cross voice or speak to them as if they were a child
- Overload their brains with information or a noisy environment
- Talk about them in the third person as if they weren’t there
- Offer too many choices between different options
- Rush them to do something, or make a decision, or finish what they are saying
- Make them try to remember a particular person or an occasion from the past
- Correct them or make them feel inadequate (ask yourself: ‘does this really matter?’)

‘my husband brightens up whenever I take him for a walk outdoors – he mimics the bird calls, their trills and swooping shrieks’
Lesley



‘Sometimes I get irritable and raise my voice – then I can see I’ve upset my husband, so I say “I need a hug” and we have a big hug, which puts us back on an even keel’
Christine

‘I’m trying to find the borders between not humouring him, not giving up on the possibility that we can make sense of any confused conversation and, on the other hand, not pulling him up on stuff he’s forgotten’
Helen

‘It is too easy just to brush over him to fill the silence with others starting to talk again – so I keep the rest of the family around him quiet while he is trying to assemble his thoughts to talk’
Sue M

Some questions for you

Here are the questions we asked people when we began writing the booklet; perhaps you'd like to think about how you would answer them?

Thinking about the person with dementia with whom you have (or had) a close relationship:

1. What do you think you personally do (or did) particularly well in communicating with them?
2. What would you most like to have known about good communication skills when you first started to look after or visit them?
3. How has (or did) that communication process changed over time?
4. What – if anything – do (or did) you dislike about the way other people try to communicate with the person?
5. What advice could you give to other carers and family members about good communication?
6. What advice, if any, would you like to give to professional staff about appropriate communication?

'I see my mother not only as a 'patient' and 'sick', but as an artist, spinning the poetry of a private world'
Elinor Fuchs, writer

Example Four

[The writer and her mother play a linguistic game initiated in response to the alliteration of her new care home, 'Chevy Chase House'. They improvise a routine.]

Lil: *"Is it very . . . hah-hah?"*

She winks, twinkling across her failure of language.

"It certainly is."

Lil: *"You mean it's a little [snapping her fingers] zu-zu?"*

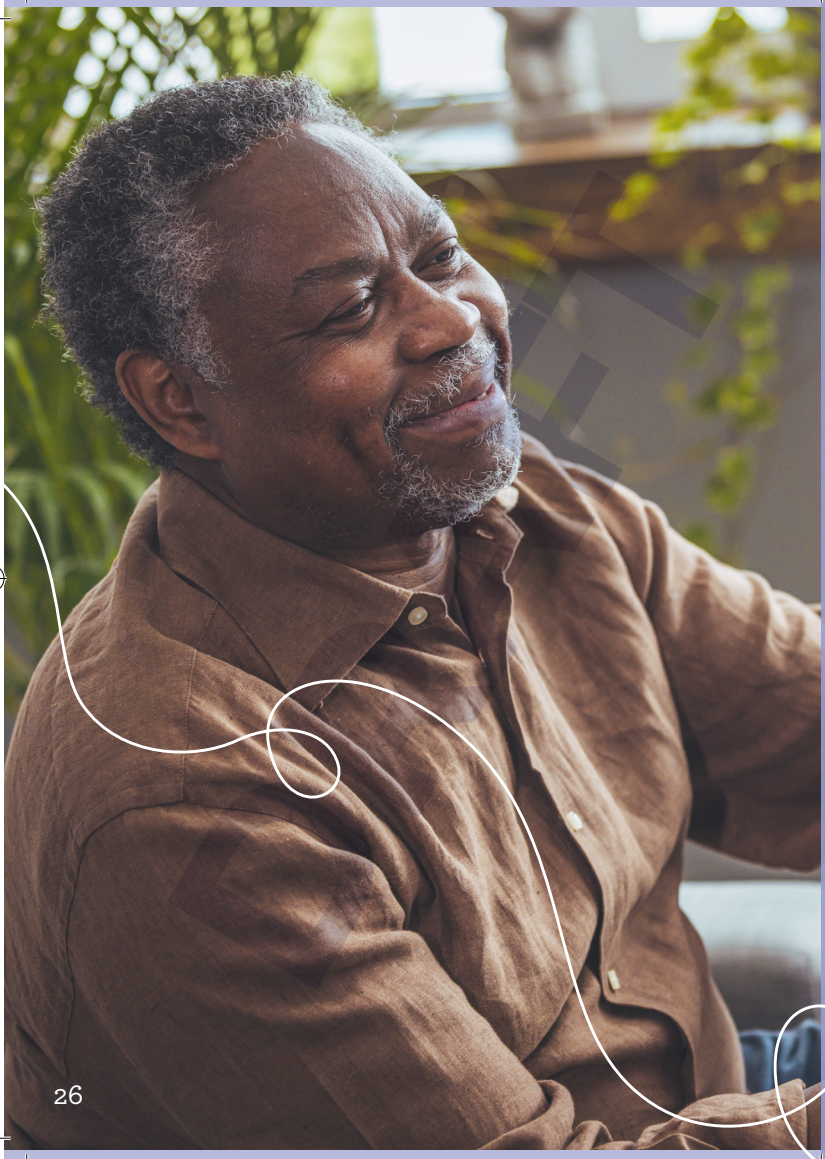
I consider the monthly bill:

"Absolutely".

Lil starts to cha-cha and do the shimmy.

"So then it's hunh-hunh?"

I hold the door for her and she shimmies out. We are laughing so hard we are crying.



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We would be very grateful for your comments on this draft booklet, and there is a separate feedback sheet tucked inside the booklet.

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