

Building up a toolbox of strategies for communication

In this first of a series of four articles on communicating with a person with dementia, Clare Morris invites readers to explore how it might feel to have dementia, and how the anxiety we feel when a conversation doesn't "make sense" can make us respond in ways that hinder communication.

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This series of articles attempts to develop an understanding of the experience of symptoms of dementia for the person with dementia, in order to provide the caregiver with a framework to make communication easier.

This first article invites readers to explore the nature of the symptoms by identifying them in our own everyday experience, and deals with some of the issues that arise in communicating with someone who has dementia. Subsequent sections – on denial and challenging behaviour, confusion and disorientation, delusions and hallucinations – look at specific difficulties that often arise, and make suggestions for strategies to help the situation.

The experience of dementia

Unusual behaviour and problems with communication are commonplace in caring for someone with dementia. These communication problems are closely related to, and are sometimes the cause of the difficult or unusual behaviours that can be so distressing for both the person with dementia and the carer. Understanding and responding to communication problems and behavioural difficulty are arguably the two most challenging and stressful aspects of caring for someone with dementia.

First I would like to invite you to explore how and why these problems may be arising, in order to understand the way in which the person with dementia may be seeing things in general, and an isolated event in particular. Equally important, it may also help the understanding of communication breakdown from the carer's point of view.

We ourselves are likely to have examples in our own lives of completely healthy errors in memory or thinking:

- Have you ever mislaid something that you know you put in a safe place?
- Have you ever woken up and been unsure where you were?
- Have you ever been greeted by someone as a friend but not been able to place them?

- Have you ever started to say something and lost track of what it was you were trying to say?

Try to recall how you felt, what you did, and what in other people's attitude or behaviour helped or didn't help you to resolve the incident. It is a good idea to do this with a friend or colleague. It provides us with many clues as to how someone with dementia might be feeling most of the time, and perhaps suggests strategies you can use to minimise both their distress, and your own. Not being able to understand what someone is trying to say fills the listener with anxiety and frustration too.

While we are unlikely to be able to put ourselves in the shoes of someone who has dementia, it is the attempt to do so which often yields fruit. To understand something of the possible reasons for strong emotions and challenging or irritating behaviour can help us to stand back and find different ways to cope. It is easy to see that being unable to express ourselves is frustrating. However it is only

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when we look at our own and others' feelings and actions in response to normal lapses in functioning that we can identify practical ways to try to relieve this frustration.

An important theme that emerges for all of us is a sense of feeling stupid, angry, frightened,

lost and anxious. There is a tendency to "cover up", particularly when the person involved with us in the situation is not well known to us. We tend to accuse and blame others for our failure.

The kinds of behaviour that help ease the situation for us tend to be when we are not ridiculed or laughed at, but our dignity is left intact; when we can gather clues to help reorientate ourselves; and when someone sympathises with our problem by correctly acknowledging our feelings in a given situation. Sometimes we feel better when we are allowed to move on in our interaction without dwelling on our "mistake"; however it can also be important to have experiences like these addressed in a sensitive way.

We are all different from each other and

experience what happens to us and around us in our own individual way. However the person with dementia, in addition, is likely to be experiencing the world in a distorted way because of damage to their brain affecting vision, hearing, smell, touch, balance, memory, language and thinking. As a result they are likely to feel very insecure, anxious, paranoid and frustrated. Experience suggests that it can be useful to assume that the way they see things is true and real for them, and to try to step into their shoes as far as is possible.

Unexpected responses make us anxious

Having a conversation with someone with dementia can be a difficult undertaking for which we are very unprepared. We communicate on many levels, verbally and non-verbally; some people are more gifted in communication skills, others less so. However, we all communicate automatically. We come to do this by years of experience, developing our own theories and making predictions about the "rules" of conversation. When people don't fit in with what we expect, this often makes us anxious. We may behave in a number of different ways to reduce our anxiety, although again we usually do this automatically, almost without thinking.

There are four common reactions to the anxiety generated when we are caring for someone who does not seem to "make sense", which you may recognise:

- We may conduct a monologue: the person with dementia and their caregiver carry on "parallel" conversations but neither is listening or responding to what the other is saying. Communication is therefore always one sided.
- We may speak and make decisions for the person: "Does he take sugar?"
- We may try "reality orientation": the person with dementia is corrected and an attempt is made for them to be "reorientated" to the "real world".
- We may find collusion easier: the carer goes along with the person with dementia's disorientated communications.

For example, an elderly woman might say: "I had a row with my mum last night". People might choose to correct the woman and point out that her mother is dead therefore this couldn't have happened; or choose to collude with her by perhaps saying: "Oh dear, poor you, what did you argue about?" and go on getting her dressed.



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Problems with these strategies

Issues arise with all these strategies for communicating with people with dementia:

Conducting a monologue and speaking for the person. Here there is no exchange of information. The person is effectively living in their own private world. But two way communication is a vital part of human existence. We are social beings, and the experience of dementia is often socially isolating, depriving the person of "normal" sensory input (because of brain damage they are not hearing, seeing, feeling and perceiving the world as we are). A sense of having an effect on your environment is central to well-being, and social isolation may possibly be the cause of many of the secondary symptoms of dementia. What is important is that we respond to the person with dementia's communications; that there is an exchange of meaning. We need to ask ourselves the question: in what circumstances would this communication make sense? We need to use our knowledge of the person and the experience of dementia to fill in or "de-code" the rest of the "message" on their behalf.

Reality orientation. Here we require the person with dementia to attempt to remain in our "reality" (to see things as we see them and interpret events as we do) – even though they are unable to do so. This confronts the person with their own failures, which they may well prefer to ignore, and in practice it seems to give rise to many

different responses ranging from anger to withdrawal. In this context it is important to consider how much the person with dementia feels they are on "shifting sands". At any moment they may lose the track of what is being said or thought. The more they feel insecure, the more they question themselves and the more their trains of thought fall apart.

Collusion. It can be very tempting to go along with the person's confused attempts to engage in conversation. However, people with dementia often have "lucid moments", good days and bad days, thereby taking you by surprise. The stories that develop can get very complicated the more people become involved, and maybe other people will be responding in different ways, by correcting them for example.

Perhaps "lying" (although this may apparently be what the person with dementia is asking you to do) may weaken their faith in you and "reality", perhaps causing the person

with dementia to become more confused. It may represent an immediate solution to the problem of talking with someone who is confused, but may do little to help the person with dementia.

Being honest but perhaps economical with the truth, and responding to people's feelings and what they might be trying to share, rather than the truth or accuracy of what they say, can be a more constructive way forward. In the example above, where an elderly woman is talking as if her mother is alive, it might be more appropriate to ask whether she argued a lot with her mother... Does she miss her mother? What was her mother like?

This promotes interaction, and often the person with dementia begins to talk in a more orientated way, about her mother but not as if she were in the here and now. Perhaps the person with dementia is talking this way because they find themselves being washed and dressed and cared for as if they were a young child, and this brings up memories of their relationship with their mother. This will be discussed in greater depth in subsequent articles.

A creative approach

To achieve two way communication the onus is on the carer to be creative in their approach by as far as is possible attempting to put themselves in the person with dementia's shoes. In all of our relationships with people we are attempting to stand in the other person's shoes in order to understand them. We use our own experience and what we know or can guess

about their experience (among other things what they like, dislike, believe in, their life history etc). This, too, is important for people with dementia. However, because of difficulties in communication and/or memory, we need to become familiar with their life story in order to interpret what the person with dementia is trying to say to us, to make it possible for them to take part in two way interaction.

How the brain is affected

In communicating with someone who is experiencing the symptoms of damage to the brain, it may help to take into account what parts of the brain are affected, and therefore what actual and what possible neurological impairments affect the person. A basic understanding of the functions of different parts of the brain can help our observations.

The lower part of the brain (known as the brain stem), is responsible for many basic functions including alertness and activity. Damage to this part of the brain affects consciousness.

The middle parts of the brain receive, process and retain information from the external world. For example information from all five senses (sight, hearing, touch, smell and taste) is integrated here. Memory can be affected by damage in several areas of the brain but particularly the inner parts of either side (the medial temporal lobes).

The outer or top layer of the brain (the cortex) is the part that organises, executes and inhibits thoughts and behaviour. This is the processor in our computer (the brain).

Someone with damage to the front part (the frontal lobe) may be able to learn, perceive and remember but may have little control over the way they behave. Antisocial, obsessive behaviour, lack of concern for others, apathy and an inability to recognise that they have problems are all features of damage to this area of the brain. Any, but not necessarily all, of these symptoms may occur in different people or at different stages of the same illness.

Damage to the back of this layer (the occipital lobe) causes problems with vision. Damage to the left side often causes problems with language, damage to the right side may cause visuo-spatial problems – problems with recognising how bits of the world fit together.

The structures underneath the top layer are known as the subcortex. Damage to these structures often produces a “slowing of transmission” giving rise to the slow ponderous thoughts and actions characteristic of vascular dementia.

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Impairments may explain behaviour

This is a very general introduction. We can go into far more detail. However, what is more important with respect to the way people relate to and communicate with each other is not primarily to identify the actual impairments and losses (often very difficult if not impossible to do) but to keep in mind possible impairments that might explain why a person is behaving in a particular way, and to appreciate what abilities are preserved.

For example, various forms of visual difficulties can occur. Difficulty with perceiving how near or far away something is; not seeing everything in view but having partial vision with sections missing; difficulty distinguishing something against its background; and difficulty tracking a moving object – all these could cause problems (although not necessarily). Each of these difficulties can give rise to a wide range of behaviours. For example being “blind” and yet recognising someone across the room; believing a caregiver to be attacking or abusing them because they haven’t seen the person approaching; withdrawal because they can’t make sense of what they see; or even helping themselves to food from the wrong plate.

Perhaps the most important visual problems that are often misunderstood are:

Illusions. Do you remember as a child thinking, in the half light, that clothes on the bedroom chair were a monster or an intruder? The person with dementia may often misinterpret what she or he sees. These misperceptions or illusions may lead to a simple mistake, or result in strong emotions such as fear, anxiety or anger.

Visual agnosia. This is a separate condition where the object is seen clearly but not “understood”. It may either be seen as something else, or just not recognised.

A toolbox for communication

Different strategies for communication will be addressed in relation to specific problems in later sections. It might be useful to

think of them in terms of a “toolbox” which can be added to. You have alternative strategies at your disposal and can try them out in different situations with different people, in light of the way the person with dementia is making sense of the event at hand. The emphasis is on trying out different strategies, as an experimental approach to communicating and caring for someone with dementia. It is a creative process unique to the individuals involved, and the “tools” needed may change over time.

In the following articles an attempt will be made to describe and explain some common difficulties that arise when caring for someone with dementia. While everything here is grounded in clinical experience as well as theory, it is intended to offer ideas and suggestions, rather than giving a “recipe” to follow. Every person with dementia is different; there are no hard and fast rules on what to say or do. I can only give guidelines, encouragement and support to enable you to be creative in the way you interact. Try things out and discuss them with fellow carers or with your family and friends.

Feedback please

I would welcome any feedback about the usefulness of this article, and although I cannot give specific advice about people not directly under our care, please contact me at CANDID (0171 829 8772 or c.morris@candid.ion.ucl.ac.uk) if you would like to discuss this approach.

Most important, however, is for each person to try to develop a support network locally in order to share and imagine the reasons why someone with dementia behaves as they do, and different ways to respond to it. If you are able to create such a support system for yourself, it can not only take some of the stress out of caring but also can make what is understandably a very challenging experience, a much more rewarding one.

Further reading

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