

Hallucinations and delusions: what you see is real for you

Clare Morris discusses the difficulties hallucinations and delusions pose for the person with dementia and their carer, in this fourth of her series on communication.

Delusions are often the source of enormous distress to both the person with dementia and the person caring for them. The definition of a delusion is "a false, unshakeable idea or belief...held with extraordinary conviction and subjective certainty" (Sims 1988). The range of delusions seen in people who have been diagnosed with dementia are listed in the panel (right)..

Jones and Burns (1992) suggest that the causes and manifestations of psychotic behaviour in dementia are qualitatively different to those observed in other populations, and that medication is of little benefit in controlling symptoms. Decreased and/or distorted sensory information, social isolation, and a damaged information processing system trying to deal with this impoverished raw material – these factors are thought to be linked to the experience of hallucinations and delusions in people with dementia.

What you see is real for you

If you accept the view that what you see is "real" for you, and that the only check on this is what other people say *they* see, then some of the behaviour of people with dementia might make more sense. Have you ever been in a position where you have held a view very different from all those present? How did you feel? What did you do? In some circumstances we might feel pressurised to alter our opinion, either climb down and agree with the prevailing view, or become more "woolly" about our belief. Perhaps we defend our position vehemently. Perhaps we come to "know" we are wrong.

In previous articles I have outlined the ways vision can be affected in brain disease (*JDC* Vol 7 Nos 4,5,6) in addition to the other problems people with dementia may have in processing information generally. Add to this the strong feelings about getting things wrong and feeling incompetent, which may account for the sensitivity and defensiveness that people with dementia often show when they are aware something is amiss but cannot acknowledge it. It seems important not to treat delusions merely as symptoms

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of brain disease, but to look closer at communication strategies that may alter the person's experience.

This is an area that deserves more research. Where is the division between truly organically induced delusions and misperceptions? We all misperceive all the time, but check our perception against what we expect to see. We know that people with dementia tend to remember things in the remote past better than recent events, therefore the belief system developed earlier in the person's life may be more accessible and more "efficient" than more recent revisions to their understanding of the world. Is the person's mind merely running amok? These are theories that need testing in relation to individual people's experiences.

Vera

Vera, in her early 70s, had been admitted to a psychogeriatric ward for assessment of her memory and behavioural difficulties. She developed a conviction that she was being raped each night by another patient, and despite reassurance to the contrary, the allegations against this man escalated. When it was acknowledged that she must have felt very frightened in such circumstances, she calmed considerably. She talked more about what she believed had taken place, and then confided that she wasn't sure any longer whether it had actually happened. This woman had extensive visual difficulties, and had personally experienced rape and torture in Auschwitz. The man she had consistently pointed out, though probably incapable of rape, spent days and nights often in only an incontinence pad, wandering in and out of the ladies dormitories. After her feelings had been acknowledged, and further information sought in a sensitive way, this elderly lady did not complain of assault again.

The need for a theory

Raymond, a retired doctor, with children of school age, developed delusions concerning the onset of Pick's disease and his daughter's eating disorder. While he has difficulty understanding things from another's point of view, he is still able to observe the "apparent" effect of his condition on his family – stressed wife, anorexic daughter, both daughters wanting to board at school... A while ago someone from the church had visited them and talked of satanic practice. At the time Raymond had dismissed this as "hocus pocus", but now he became convinced that she had cursed their household and caused his and his daughter's illnesses. He was therefore insisting on

Types of delusions seen in people with dementia (source Harvey 1996)

- Theft: Complaints of people breaking into the house to steal or hide things.
- Phantom boarder: Other people living in the house: making extra cups of tea, laying an extra place at table.
- Persecution and endangerment: Beliefs that people are 'out to get me', or that food is being poisoned.
- Spouse infidelity: "You are seeing someone else behind my back".
- One's house is not one's home: The person may ask, "When are we going home?", while at home, or if the delusion is more strongly held, may leave in search of "home".
- Delusions of infestation: Belief that the home is infested by small organisms eg spiders, worms, ants or lice.
- Picture sign: Believing their mirror image is someone else, either in the room or in a picture.
- Delusions relating to the television: The person loses contact with the boundary between reality and TV, believing that events in the TV programme are happening to the person in real life.
- Abandonment: "You want to put me in a nursing home".
- Delusional misidentification (Capgras and Fregoli Syndromes): "You are not my husband, what have you done with him?" – the belief that a familiar person has been replaced by an imposter who looks like that person.
- Delusions of love (De Clerambault's Syndrome): The belief that a prominent, famous or otherwise unreachable person is secretly in love with them.

having their house exorcised.

Frontal lobe dementias cause difficulty in anticipating and recognising the needs of others, and perhaps this was the only way he could understand and explain his family's problems. He described his family as previously living a "charmed existence"; but now it was all falling apart. His wife refused point blank to comply with exorcism. Reasoning with him did not help at all. After a while, however, he came to rely on "trust" that her judgement was now better than his (presumably a result of their previously strong marriage).

Raymond now either keeps his theory to himself or it longer concerns him. If due to brain damage you find it difficult to anticipate and recognise the needs and feelings of others, let alone be able to relate it to your own behaviour, but observe such distress in the people you love, perhaps it makes sense to question your beliefs.

Peter

Peter has a memory span of ten minutes – a complication of viral encephalitis. He developed intricate theories about how he became amnesic, ranging from a little girl sitting on his lap and infecting him, to a vengeful deity. If you can't remember what has happened, it appears that there is a need to generate a plausible explanation, a theory to put one's situation in context.

Hallucinations

A hallucination is a voice or a vision (or feeling or smell) that occurs without any stimulation. Auditory hallucinations (voices) are common in schizophrenia. Hallucinations (usually visual) are particularly common in Lewy body dementia. Some people show considerable insight into their experiences, others find it difficult to distinguish hallucinations from reality. There is considerable stigma in "seeing things" – it has an association with madness. As a result, people with dementia who experience hallucinations are sometimes reluctant to talk about them. Desmond, before his clinic appointment, joked with his friend that of course he could talk to the doctors and nurses about his problems, as long as he didn't tell them the truth!

The other important issue lies in the anxiety people feel when affected by hallucinations. How do you know when you are hallucinating and when something is "real"? It is easy to imagine how hallucinations could lead to paranoia if not appropriately and sensitively handled. Someone living alone will have no trusted confidant with whom to make reality checks. Given the taboo, and the pervasive insecurity that results from cognitive impairment, is it surprising that people sometimes feel mistrustful of family and friends?

Regular hallucinations are very unsettling and often disturb sleep considerably. Lack of sleep will also affect the person's well being and ability to cope with distressing symptoms.

Caring for someone experiencing hallucinations can be immensely distressing. If we can help them to understand that these are symptoms of the disease, and help them to stand in the person with dementia's shoes in order to assist them in dealing with the experience, it can go a long way in helping carers to cope.

Eileen

Eileen regularly sees people in the house, and insists at times that her husband isn't her husband. When reasoned with, and his identity "proved" she often rejects this as insufficient, but some-

times concedes that he is a "different Arthur", or that they could be "friends". She will refuse to give him his mail and goes round to the neighbours to check what he says is right. But if you stop and consider how much has changed since his wife developed dementia, it is clear that he now has a very different role as carer – cooking, cleaning and taking care of his wife – as opposed to his previous more "male" routine of going out and playing golf three times a week. She is right: he is different.

She also has difficulties with recognising faces and remembering recent events – in addition to the hallucinations where strangers are in the house interfering in her affairs and having sex behind the curtains. Given the enormous changes in role and losses associated with those changes, the distorted sensory input, and disturbing hallucinations, she must be confused and frightened. Is it not understandable that a person in these circumstances would be suspicious about people's motives?

Work is in progress to acknowledge the losses and practical difficulties that Arthur faces. Failing to be recognised and accepted as her husband of 45 years affects a person very deeply, in addition to the problem of managing the situation from moment to moment. We are also looking at ways that he and his son can adopt a problem solving stance together, to see if Eileen during her lucid moments can give clues herself as to how to manage her symptoms, and to see if particular ways of responding have any influence on their quality of life.

Medical treatments

Antipsychotic medication has been used to treat hallucinations in dementia with limited success. Hallucinations, delusions and perceptual problems are common in dementia with Lewy bodies, but the affected person is very sensitive to this type of medication. It can often cause severe postural side effects and an escalation of symptoms which can prove fatal. Experts recommend caution in their use (Harvey, Fox & Rossor 1999).

Allistair

Allistair regularly saw angels at the bottom of the bed. He became very distressed when his wife assured him they were not there. Melleril (thioridazine) was prescribed to reduce the symptoms, however this had no effect and caused severe postural side-effects. Previously he had walked long distances with his wife but he was subsequently unable to manage this, and therefore unable to accompany his wife on everyday errands. This distress was far greater for

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both Allistair and his wife as he had to be locked in the house against his wishes and could not understand why. He communicated clearly that life was no longer worth living and he could not bear the effect his behaviour was having on his wife. Allistair died three months later. (This example comes from several years ago, before dementia with Lewy bodies and the effects of Melleril had been recognised.)

Developments in medical treatments

Deficits in the brain of the chemical acetylcholine are a hallmark of Alzheimer's disease (AD). This transmitter plays numerous complex roles in our cognitive processes. The low levels found in AD can be raised by prescribing cholinesterase inhibitors – drugs such as donepezil hydrochloride (Aricept) and rivastigmine (Exelon) which inhibit the breakdown of acetylcholine. These have been shown in clinical trials to improve cognitive functioning in AD.

There is some evidence to suggest that these drugs might be useful in treating a dementia with Lewy bodies where hallucinations are a major problem. We know that a reduction in the brain's acetylcholine levels can produce confusion and hallucinations in apparently cognitively healthy elderly people (for example people with Parkinson's disease), so one can speculate that in AD, dementia with Lewy bodies or acute confusional states, it might be possible to improve cognitive function and reduce confusion and hallucinations by boosting acetylcholine levels.

Neurotransmission in the brain is, however, much more complex than this might lead us to believe. There are many transmitters that interact with each other in many different ways. In the future we may look at each individual's particular pattern of deficits and target

therapies specifically. For the moment, however, we have one class of drugs which produces some symptomatic improvement in some patients (Fox 1999).

Conclusion

This and the last article in this series are not intended as a definitive account on managing behaviour which arises from the wide range of perceptual difficulties that can be present in brain disease; there is enormous scope for further development in understanding. In my experience it is important to be credulous and open to clues about people's experiences.

It seems to me that we can only ever approximate an understanding of the experience of these symptoms, but in general it helps to take the view that all behaviour makes sense in light of the way the person sees events, and to accept that the way the person sees things is real and true for them at that moment in time. Helping the person caring for someone with dementia to adopt this view can empower them to deal with very challenging behaviour. Understanding the enormous range of visual disturbances that affect people with brain damage; the fact that people may well not be aware of their difficulties and that people's ability to compensate is enormously variable; that many symptoms can co-exist in dementia making it difficult to ascertain exactly what someone is seeing; and that symptoms can fluctuate causing symptoms to be present at times but not necessarily all the time – all this may help to solve some of the difficulties that arise in caring for someone with dementia.

Finally, there are always symptoms described that don't necessarily fit into our current understanding. Derek talks of seeing everything in red. He only knows that isn't right because his wife's hair is red, and he knows that it is really grey. He also describes a prickling sensation all over his body which is only relieved by walking. He regularly talks to "people" and packs his bags. He seems to deal with the situation philosophically: "I've had a good life and we must get on with it. Thank goodness for my wonderful young lady".

References

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Next issue: Language, memory and confusion.