

CHANGES IN BEHAVIOUR

As someone's ability to remember, reason and speak diminish they have to express themselves in a different way. This new way to communicate is often via new behaviours. Those close to the person with dementia often learn to interpret what a certain behaviour means. For example, a man fumbling with his belt needs to go to the toilet, a woman paces when she is anxious, someone who resists getting dressed is in pain. As support people come to understand what a behaviour communicates they can deal with the person's need rather than focussing on the challenge produced by the specific behaviour. The *Spark of Life Programme* asks of a new behaviour, "What is the unmet need?"

The **physical** needs of people with dementia are many and varied: pain, feeling cold/hot, hunger, tiredness, full bowel or bladder, shortness of breath etc. The **environment** needs to be considered as well: is it noisy, under- or over-stimulating, stuffy, unattractive, lacking outdoor access, institutional rather than homelike and familiar?

The **psychological** needs of people with dementia (and all of us) have been summarised by Tom Kitwood:

- attachment –needing to be close to someone you trust,
- comfort – physical and emotional,
- identity – being recognised for who you are – yourself as a unique individual,
- occupation –something meaningful to do,
- inclusion – feeling of part of the group and,
- central to all this, the person with dementia needs to feel (and be) loved.

Often it requires a lot of imaginative detective work to discover what a certain behaviour means. **Knowing what the person with dementia was like** before they developed the condition, about their history and interests is essential. For example, an anxious person will become more so if they can't remember where they are or what they are meant to be doing, someone who was always outdoors in the garden will become agitated if confined to the lounge, a very private man will push away female caregivers trying to shower him, a woman abused as a child may be terrified when taken to the toilet. Consider whether there are any particular events that might have triggered this behaviour. **The stage**

and type of dementia may indicate particular issues. For example the spatial awareness problems in Lewy Body dementia might mean that a person is afraid going into small spaces like a toilet or problems in the visual recognition area (occipital) part of the brain could mean that he or she misinterprets what they see. Repeated questions often reflect memory impairment; for the person it is the first time they have asked the question. The time of day matters to some people in the mid-late stages of dementia who become agitated in the late afternoon ("sundowning"). **The medical condition** of the person also matters a great deal. One third of people with dementia with changed behaviour are in pain, and problems such as constipation, urine infections or heart problems are easily missed in people with dementia

An approach to manage behaviour change might be like this:

1. Does the behaviour matter? If it is not causing distress to anyone including the person with dementia, does anything need to be done. (Examples might be eating messily or talking to people on TV.)
2. What might be the cause of the behaviour (the unmet need)? Try to work this out by observing the person and thinking about their past history, interests and ways of dealing with stress. If they seem bored, consider whether something that interested them in the past could be made available to them now, for example personalised music, familiar books or stories, watching sport, craft, or engagement in household activities or gardening.
3. A medical review might be needed to treat pain, infection, depression, constipation or another

condition. Sometimes a new medication has an adverse side-effect.

4. Think about the environment. Is there anything that is annoying or uncomfortable e.g. a TV which is noisy and hard for the person to understand, a cat near someone who hates cats? Can the person find their bedroom or favourite space and when they get there does it feel familiar with personalised items?

How to handle behaviour that is distressing

- Make sure the emotional tone is pleasant. People with dementia easily pick up others' feelings of frustration, anger or despair and may feel frightened they are going to be abandoned. For example, "shadowing" i.e. sticking closely to the carer is an expression of anxiety and fear of being alone. Affection and reassurance help those who are anxious and humour- laughing at both of you- relieves tension and brings you closer together.
- Don't overtax the person. While it is important to keep the person with dementia active and involved, you will often need to break down tasks into simple steps that are achievable to avoid frustration and distress.
- Use your best communication skills (FACT SHEET # 4) to understand what the person

wants and to explain what is happening. Make sure the surroundings aren't distracting, get the person's attention, make sentences direct and uncomplicated, ask simple "yes" and "no" questions, all the time make sure that your body language, gesture and tone of voice are reassuring and relaxed.

- Distraction. Often an offer of a walk or a cup of tea or coffee – changing the environment or topic- will stop distressing behaviours, for a while at least.

Remember the person with dementia finds it very hard to learn new things. It is the people (and environment) who have to adapt to the behaviour changes. Fortunately, you are not on your own. Talking to others who have had to deal with similar situations can be very helpful and reassuring. You don't have to be perfect (and won't be), so don't be too hard on yourself if you lose your patience or temper. Everyone is unique and there is often no approach that works every time. Make a note of what has worked in the past and try to have a range of things to try that seem to be helpful. Share your experiences with others and share the load.

Get support from:

Dementia NZ

This publication provides a general summary only of the subject matter covered. People should seek professional advice about their specific case.

Dementia New Zealand offers support, information and education.
Ring 0800 4 DEMENTIA or 0800 433 636.
Or visit our website at www.dementia.nz