

UNDERSTANDING BEHAVIOURS

Providing support for people with dementia is a rewarding experience, but can place demands on a carer's skills and resources. There are a number of behaviours that carers may find challenging including restlessness, pacing and wandering, repetitive questioning, constantly following the carer, unpredictable emotional outbursts and apathy. Other behaviours include inappropriate toileting or social behaviour; and disturbed sleep patterns. Information about and understanding of these various behaviours will help carers to cope.

Behaviour will vary from person to person, and individuals will react to circumstances in their own way. Sometimes the behaviours may be related to changes in the body or brain, and in other instances to environmental factors such as who is around and how others react, or to what the person was like before they had dementia.

It is important to remember that people with dementia are not usually trying to be deliberately difficult. Many of their behaviours are due to an attempt to communicate what they want or how they are feeling. There are times when a person with dementia will become so frustrated with their inability to communicate that they may act out. Once we understand the reasons behind a behaviour, then it is usually easier to cope with it.

Physical Considerations

- Consider any illness or infection a person with dementia may have: urinary tract infection, ulcers, chest infection, arthritis, angina, constipation. Pain or discomfort may cause agitated behaviour or reduced level of functioning. Don't automatically assume that dementia is the only cause. For example toothache and tooth decay may be present with no obvious signs or swelling of gums. Be especially aware of sudden changes or deterioration as these are often a symptom of something physically wrong and not just dementia. It is also good to look out for non-verbal signs that can indicate some sort of illness.
- Ask your doctor about the side effects of the medication a person with dementia is taking. Tablets and medicines can cause confusion or agitation. Sedatives given to help the person sleep can affect bladder functioning, causing incontinence or urinary retention.

- Physical discomfort from being too hot, too cold, or needing to go to the toilet is an important consideration.
- Sometimes a person with dementia may forget to drink resulting in dehydration. Insufficient fluid may cause many different problems including dizziness, headaches, dry skin, infection, cramp, constipation, urinary problems and increased confusion.

Environmental Considerations

- Sometimes people who have a stooped posture and are sitting in a normal chair can become very distressed, because they cannot see higher than their knees and cannot communicate. A recliner chair to raise their vision can have remarkable results.
- Too much stimulation in the environment, e.g. TV, radio or other loud conversation, may upset or frustrate a person with dementia. Crowds, busy traffic, large gatherings and fast-moving people can create agitation. Many people with dementia often find wearing earplugs in crowds very helpful. Too little stimulation on the other hand can cause dissatisfaction and frustration.
- Lighting and use of patterns and colours can affect a person's behaviour. The use of a nightlight or diffuse lighting may be beneficial. Patterned floor tiles, changing from vinyl to carpet, steps or an uneven surface, may cause a person with dementia to trip or become unsure where to walk.
- Routine is important to a person with dementia. Problems may occur because a routine has been altered. It is important to remember that some flexibility in the routine may be necessary to cope with the changing moods of the person. Being in a new and unfamiliar environment can also be distressing for a person with dementia.

Analysing the Problems

Dealing with challenging behaviours on a regular basis can be difficult. However, understanding why problems occur and changing the way you behave towards the person can make things easier. It may be beneficial to keep a journal or diary of these events.

1. **Identify the main problem.** Deal with the most pressing problem first, i.e. the one that occurs most often or causes a person with dementia and

the carer most stress. It is vital that at all times the safety of both persons is maintained.

2. **Is it really a problem?** For whom is it a problem? Can you accept this behaviour rather than try to alter it?
3. **Identify the possible cause(s).** Identify what might trigger a particular behaviour at a specific time and place, e.g. what was happening beforehand and who was involved. Patterns may emerge that will show why certain behaviours have occurred.
4. **Think objectively about your caregiving style.** Try to avoid hurry and bustle, provide distraction, avoid treating the person like a child, give choices, communicate clearly and simply with a calm voice and gentle touch.
5. **Look at possible options.** Think of as many options as possible. List each alternative, consider pros and cons, try one at a time. Talk to others about the situation – they may have suggestions. Carer support groups are available at your local Alzheimers organisation.
6. **What worked?** If the behaviour that you find challenging is occurring less frequently, the plan is working. Remember, problem solving is a process of trial and error; there are no simple solutions. What works for one person will not necessarily work for another and what worked once may not work every time.
7. **It may not always be possible to solve the problem completely.** Reducing the frequency or severity of challenging behaviours (increasing the length of time between them) may be as much as can be achieved. Walking away and allowing someone else to spend time with the person to allow yourself time out might be helpful.

Some General Management Strategies

- Rule out physical and/or medication problems – discuss with your doctor.
- Distract with food/drink or activities (try simple chores or hobbies, walking, dancing, music, reading, or massage).
- Alternate quiet times with more active times; try rest periods to minimise fatigue.
- Reassure with a calm voice and gentle touch; if this doesn't work, sometimes ignoring the behaviour does!

- Keep things simple and routines reasonably regular; use written reminders and signs.
- For sleep problems, try leaving on a night light to assist orientation (e.g. to find the toilet).
- Keep expectations realistic – it can cause difficulties if a person with dementia is given a task which is no longer within their capabilities.
- For angry behaviour, try to keep calm; approach from the front so you can be seen; keep yourself safe.
- Limit stimulants eg alcohol or caffeine.

Remember that some behaviours may be due to a person with dementia realising that everything is not quite right. Our attempts to help and do things for this person may inadvertently highlight the fact that their competence is failing. It is therefore beneficial to try to help the person to maintain independence as long as possible.

Abuse of a carer is unacceptable. If you are being physically or psychologically abused by a person with dementia you should seek help urgently. Elder Abuse and Neglect Prevention Services are established throughout the country and co-ordinate responses to cases of abuse and/or neglect of older people. Alternatively you can contact your GP, community constable or local Alzheimers organisation for help and advice.

Caring for a person with dementia can be stressful and frustrating; however, abuse of a person with dementia is not acceptable. If you are having trouble caring for a person with dementia, then it is important that you seek help. Asking for help is not asking someone to take full responsibility, nor is it an indication of failure. Attending a Carer Education Course run by your local Alzheimers organisation may help you learn how to manage and understand challenging behaviours. Attending Carer Support Groups may also help you to learn from others and gain some added support. It is also important that as a carer you support yourself and take breaks when you need them.

See Alzheimers New Zealand Information Sheet Fifteen "Caring for the carer" for more helpful ideas.

Alzheimers New Zealand has a range of information sheets and booklets available for people with dementia, their carers, families and whānau. Alzheimers member organisations located throughout New Zealand provide a variety of services and support to all people affected by dementia. Contact your local organisation on freephone 0800 004 001.

This information sheet provides a general summary only of the subject matter covered and is not a substitute for informed professional advice. Any person with dementia or their carer or family/whānau should seek professional advice about any individual case. Alzheimers New Zealand is not be liable for any error or omission in this publication, as a result of negligence or otherwise. This information sheet was produced in March 2010.

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