



Carers Brochure

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DEMENTIA AND CHANGES IN BEHAVIOUR

Family members, friends and carers play an important role in supporting those living with dementia. This brochure is designed to help support you in caring for a person with dementia.

Many people living with dementia have changes in their behaviour at one time or another. Changes in the brain, changes in the person's environment, or the person feeling unwell can trigger these behaviours. People with dementia may wander, feel anxious, angry or frustrated, and behave in ways that others find embarrassing and socially unacceptable. For some people, certain behaviours increase in the afternoon or early evening. These behaviours are often not deliberate and might be the person trying to communicate their needs.

Whether you care for a loved one at home or support them living in an aged-care facility, there are certain strategies that might help. Many behaviours can be helped with the use of non-medicine options combined with good support from family, carers and the healthcare team.

In some cases, when the behaviour is very distressing or harmful, and nothing else seems to help, medicines may form part of the treatment plan.

Family members and those who care for someone living with dementia understand their loved ones, and their needs and preferences, best. You are often the first to notice changes in their behaviour and can help identify triggers as well as possible solutions.

**If you are concerned about the behaviour of the person you are caring for contact the Dementia Behaviour Management Advisory Services (DBMAS)
Phone: 1800 699 799**

Why behaviour might change and how you can help

Behaviours can vary with the type of dementia. Each person is unique in their experiences. Triggers can be complex and possible solutions will be different for each person. Here are some possible triggers and what might help.

Write down a description of the behaviour including when it occurs, who is involved, and the emotions expressed. This can help you and the healthcare team tailor strategies to manage these.

❓ Could there be a health problem causing discomfort or pain?

Treatable medical causes might include acute pain, urinary tract infection, constipation, or dehydration. A side effect of a medicine or long term health conditions such as chronic pain might also contribute.

✔ How can I help?

- Ask the person.
- Look for symptoms of pain and discomfort.
- Talk to the person's doctor if you have any concerns about their health or if you think they may be experiencing discomfort or pain.

❓ Could there be emotional and physical needs that you are unaware of?

A person with dementia has the same basic needs as everyone else but they might be less able to recognise or communicate them. Is the person feeling useful and needed? Do they have a sense of belonging?

Are they hungry, needing to use the toilet, or feeling too cold or too warm? Is their clothing comfortable and easy to manage when going to the toilet?

✔ How can I help?

- Try encouraging food they enjoy, adjusting heating and cooling, or time of toileting.
- Consider zips, velcro or elasticised waists instead of buttons on clothing, velcro fastened shoes instead of laces, and a 'modesty' cape in the bathroom (contact DBMAS for further information).
- Encourage regular physical activities such as walking, especially if they were active in the past.
- Find interesting hands-on activities to make them feel useful and needed – gardening, folding clothes, dusting, or a rummage box to sort through.
- Comfort them with a soft toy animal, music, aromatherapy or massage.
- Reinstate simple rituals such as a favourite food or sitting in the garden in the morning sun.

❓ Could the person be feeling confused or unsettled from a change in their routine or surroundings?

Their surrounding might be too large and overwhelming, there could be too much noise or activity, or there may be a new and unfamiliar routine.

✔ How can I help?

- Try to keep their surroundings and routines familiar and unrushed.
- Try limiting noise and activity.

- Make sure their personal items are close by.
- Consider using signs to help the person navigate their environment.
- Tell everyone who becomes involved in the care of your loved one, including doctors, pharmacists, or aged-care staff about their preferred routine (see insert 'Share your practical tips' for suggestions).
- Above all, make sure the person is safe.

? Could the person be feeling frustrated by not being able to do things they might have done in the past?

As dementia progresses, tasks might become too hard for the person to complete e.g. Mr Brown caught the bus to work every morning and now gets frustrated when he can't find the bus stop.

✓ How can I help?

- Where possible ask the person what they would like to do.
- Many simple activities can provide purpose and pleasure for a person with dementia. Consider their former lifestyle, work and interests when selecting them.
- Try talking about the period in their life they are referring to. Give them a memory box with photos and memorabilia from their life.
- Play familiar songs if the person enjoys music.
- Organise outings for the person.
- Look for creative solutions for comfort and reassurance (e.g. a bench outside can create a 'bus stop' for Mr Brown to wait for his morning bus).

? Could the person be finding it difficult to communicate their feelings, wants, and needs?

They might not be able to understand what is being said or expected of them. This might create confusion or frustration.

✓ How can I help?

- Listen carefully and patiently, paying attention to their body language and emotions.
- Keep things simple, and try to communicate one point at a time.
- Smile and use a calm tone to help put them at ease.
- Make sure glasses and hearing aids are working properly and are within reach.

And most importantly... make sure you look after yourself

Caring for someone with dementia can be demanding and stressful. Take regular breaks, recharge, and look after yourself. Find out if family or friends are happy to help out from time to time. Gold and white card holders (carers as well as those with dementia) may be eligible to receive respite care through the Veterans' Home Care (VHC) Program. A number of Australian and state government funded respite services are also available.



For severe behaviours, in particular when a person is at risk of harming themselves or others, medicines could be considered. In some cases, the doctor may suggest an antipsychotic medicine such as risperidone (e.g. APO-Risperidone®, Risperdal®). These medicines will not work for everyone and generally should not be used for periods longer than three months. Like all medicines, antipsychotics can have side effects at any time during treatment.

When a new medicine is prescribed always ask:

- How will it help? Are there any risks?
- What side effects might occur? What should I do if these occur?
- How often should it be reviewed? When can the medicine be stopped?

If a person with dementia is unable to consent to taking the medicine themselves, the doctor should ask for informed consent from the patient's legal guardian.

When a medicine is prescribed, keep in frequent contact with the doctor and aged-care staff. Talk to the doctor if you think the medicine is making the behaviour worse, or if you have noticed that the person is more sleepy than usual or seems more forgetful. If the person you are caring for is finding it difficult to swallow, talk to their doctor about other forms available (e.g. a wafer or liquid). If you have any concerns about the person you are caring for and their medicines, talk to their doctor or pharmacist.

Resources and services that can help

- **The Dementia Behaviour Management Advisory Services (DBMAS):** Confidential advice and specialised support for families and carers 24 hours a day. Phone: 1800 699 799
- **Alzheimer's Australia:** (www.fightdementia.org.au) or call the National Dementia Helpline. Phone: 1800 100 500
- **Relate, Motivate, Appreciate: An Introduction to Montessori Activities:** A guide to meaningful activities that carers and families can do with their loved ones (<http://qualitydementiacare.org.au/wp-content/uploads/AlheimersAustralia-A5-Montessori-Booklet-WEB.pdf>)
- **Veterans' Home Care Program:** To arrange an assessment for accessing respite care. Phone: 1300 550 450 or see the DVA Veterans' Home Care website (<http://www.dva.gov.au/providers/provider-programmes/veterans-home-care>)



Share your practical tips

Research from the TOP5 program has shown that writing down and sharing up to five important tips such as those listed below, can help others to support and care for a person with dementia¹

- Situations that might cause distress and what could help
- When the person is unsettled, the words or actions likely to help calm and settle them
- Routines and rituals that are reassuring
- Signs that indicate the person needs or wants something
- Names and photos of family, friends or pets that are important to the person
- Personal preferences for enjoyment such as music, radio, reading or gardening.

Think about the most important tips that will help others give reassuring and familiar care. Use the reverse of this page to write these down. Provide the 'why', followed by your practical tip and what will happen when this is followed (see examples).

Give a copy to anyone who helps support and care for your family member or friend including:

- Residential aged-care workers, if living in aged-care
- Home help, community groups, day care facilities, or respite care, if living in the community
- Paramedics, if using an ambulance
- Admitting nurse, if the person has a hospital stay
- Doctors, pharmacists and any other health professionals involved in the person's care

Example 1

Background/why:

Ken was a fireman for forty years.

Practical tip:

If Ken hears an alarm or loud ringing he will become distressed. Let him know that the car has been sent.

What will happen when followed:

Ken will calm down. Offer him a cup of tea and he will forget about the alarm.

Example 2

Background/why:

Mary has always prided herself on looking well presented.

Practical tip:

Ensure her hair is brushed and tell her she looks lovely today.

What will happen when followed:

Mary will be less anxious and more likely to engage with staff.



¹ Luxford K et al. Improving clinician-carer communication for safer hospital care: a study of the 'TOP 5' strategy in patients with dementia. International Journal for Quality in Health Care 2015; 1-8.



Date: / /

Carer's name:

Carer's Phone No: ()

Getting to know:

NAME OF PERSON

Practical tips on how to comfort and support them²

Background/why:
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Practical tip:
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What will happen when followed:
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Background/why:
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What will happen when followed:
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2 This has been adapted from the TOP5 program developed by the Central Coast Local Health District, NSW. Further information for carers about the TOP5 program is available at <http://www.cclhd.health.nsw.gov.au/patientsandvisitors/CarerSupport/top5/Pages/Carer-family.aspx>