



Practical Aspects of Caring

We have our ups and downs with Mum. "Can't find the toilet", so we removed the door. "Can't find my way around in the dark", so we placed a sensor light in the hall. Mum cannot use the phone, or make a cup of tea, or dress herself properly, but her health is excellent.

Mum has some reserve funds and with this we pay a lovely friend to take her out to various places such as the art gallery, concerts at the local club, and drives in the country. Mum enjoys a good week with three days at the day centre and two outing days with friends. We look after her on weekends. She still manages independent living in her own home, with our support.

Little things such as leaving the gas fire on through the winter were difficult at first. Mum kept turning the gas off, but we taped the knobs and after lots of talking the gas fire is now acceptable to her. We had to disconnect the gas stove and buy a microwave. We prepare Mum's meals and put them in the freezer and the respite care ladies come in every night, give her a meal and put her to bed.

Practical aspects of caring

Dementia progresses differently in each person. Initially there may be only slight changes in personality and behaviour. The person may be less motivated to do things that previously interested them, or reluctant to part from familiar surroundings or routines. In addition, their abilities may change from day to day, or even within the same day.

These changes will become more noticeable over time. Concentration, understanding and the ability to reason may deteriorate. People with dementia may suffer confusion, distress, mood changes and aggression as they struggle with the frustrations of everyday life.

As the condition progresses, some abilities will remain. The sense of touch and hearing are not affected by dementia.

Following are some practical ideas for caring. Many of them are tips from families and carers, and people with dementia.

Dementia and the environment

Buildings and environments have a significant effect on a person with dementia. People with dementia function best in structured, quiet and uncluttered surroundings. A person's home, because it is familiar, can usually provide a far greater level of environmental support than the newest or best designed residential facility.

Sometimes the layout, appliances and amenities of the home may need to be modified to make them usable or safer for a person with dementia. The aim of any home modification is to allow the person with dementia to maintain independence and remain living at home for as long as possible. Modifications should only be made in response to specific problems or to encourage independence or participation. It is important to change as little as possible and to retain familiar items, unless they present a problem, or are an obstacle to the person's independent functioning.

Changes will occur in a person's abilities and will require on-going assessments. Consideration also needs to be given to the gradual ageing process that may affect vision, hearing and mobility.

THE BEST LIVING ENVIRONMENT FOR A PERSON WITH DEMENTIA SHOULD

- **be familiar**
- **help the person to know where they are or find where they want to go**
- **encourage participation in tasks and activities rather than promoting passivity and dependence**
- **promote confidence and self-esteem by helping people to succeed rather than fail with everyday tasks**
- **reinforce the person's sense of identity by stimulating their memory**
- **be physically and psychologically comfortable with good lighting, a comfortable temperature, the right level of stimulation and minimal stress, and**
- **promote safety by making caring tasks safer and easier for families and carers by achieving a balance between safety, security and independence.**

TIPS TO HELP MAKE A SAFE ENVIRONMENT

- Remove loose mats, power cords and extension leads from the floors.
- Night-lights in the hallway and in the toilet may help to find the way safely at night.
- Automatic cut-offs for hot water jugs and other appliances are recommended.
- Place rails in the bathroom, toilet and next to the stairs.
- Replace potentially dangerous forms of heating such as bar heaters with safer heaters like column heaters.
- Make sure smoke detectors are installed and checked regularly.
- Check safety in the front and backyards. Keep paths well swept and check gate catches.

If you are lifting the person, make sure you get professional advice about how to do this safely, and about any aids that can help you. Back injuries are very common among carers.

The Department of Veterans' Affairs Rehabilitation Appliances Program (RAP) can assist with aids and home modifications that may be needed.

Communication

Losing the ability to communicate can be one of the most frustrating problems for a person with dementia. Some changes in communication include difficulty finding the right word, not being able to understand all of what is being said or difficulty expressing emotions appropriately. Reading and writing skills may deteriorate and there may also be age related problems with vision and hearing.



TIPS FOR CARING

- Do not rush. Always allow plenty of time.
- Keep sentences short and simple. Focus on one idea at a time.
- Speak in soft, unhurried tones.
- Try to avoid conversations that include a lot of questions that need to be answered.
- Ask questions that require yes or no answers or a simple choice of two possible alternative answers.
- Consider using hand and facial gestures to help get your message across.
- Maintain eye contact and use positive, non-verbal communication, like smiling and leaning forward.
- Use visual cues like photographs, pictures and objects.
- Try to avoid background noise such as the television or a radio.
- When several people are present, encourage the use of nametags to help with recognition.

Activities

Most people with dementia will need some assistance to participate in leisure and other types of activities. It is important that they are involved in activities that promote their self-esteem and maintain the skills that they still have.

TIPS FOR CARING

- **Make use of abilities that are retained.** For example, the person with dementia may be able to help around the house by washing up, folding linen or working in the garden.
- **Make activities simple and unhurried.**
- **Avoid activities that increase the stress levels of the person.**
- **People with dementia will have some times in the day when they function better.** Similarly their abilities may vary from day to day. Take this into account when organising activities.
- **Many people with dementia do not enjoy crowds or noisy environments.**
- **If reading has deteriorated, use recorded messages and books.**
- **Sensory experiences, such as massage, stroking an animal or brushing hair can be enjoyable for people whose abilities have deteriorated.**

Driving

Many families and carers worry about the person with dementia who continues to drive. Dementia produces a progressive and irreversible loss of mental functioning and will eventually affect the person's ability to drive safely.

Some people will recognise their declining ability and be prepared, or even relieved, to be rid of the responsibility of driving. Unfortunately, others may not recognise they can no longer drive safely or may

simply forget that they are not allowed to drive anymore. Some people find giving up driving one of the hardest things to do, as their car may be an important part of their independence. This can be a very difficult situation and needs to be handled sensitively.

In most States and Territories, drivers must tell their licensing authority of any condition that might affect their ability to drive. Dementia is one such medical condition that needs to be disclosed.

The licensing authority will provide the driver with a medical form to be completed by their doctor. The doctor will assess whether the person is medically fit to drive. The licensing authority will then decide if the driver can continue driving or have conditions placed on their licence. These conditions can include only driving near their home or only driving at certain times of the day. Regular medical and driving tests might be required.

TIPS FOR CARING

- Ensure a family member or friend drives with the person with dementia at least monthly to monitor their driving and safety.
- Help drivers to evaluate their own skills. “A Guide for Older Drivers” contains a comprehensive self-assessment questionnaire and is available from your State or Territory licensing authority.
- Encourage the person to talk to their doctor about their driving.
- Suggest good reasons for using public transport, or having someone else drive, such as being less stressful, enjoying the scenery and saving on the cost of running a car.
- Arrange outings that do not require the car to be driven.
- If safety is a major concern, hide the car keys or immobilise the car.

Hygiene

It is quite common for people with dementia to forget or lose interest in bathing or changing their clothes. Hygiene is sometimes a point of great conflict between families and carers and a person with dementia.

TIPS FOR CARING

- Make sure that a person's need for privacy is considered when undressing and bathing. Pull down blinds and close curtains and doors.
- Keep bathing and showering simple. Explain each step.
- Make sure that the bathroom is warm and comfortable.
- Provide a safe environment by using non-slip mats, handrails or a shower chair.
- Try to develop a regular routine.
- Arrange regular visits to the dentist to check on teeth, gums or dentures. You may need to help with teeth or denture cleaning or do it yourself.
- It is not always necessary to shower or bathe daily. Frequent washing can compromise the skin of elderly people.



Nutrition

The type of food we eat affects our health and quality of life. The nutritional requirements for people with dementia are the same as for people not affected by dementia.

Dietary guidelines for older Australians recommend:

- **enjoying a wide variety of nutritious foods**
- **eating at least three meals a day**
- **drinking plenty of water**
- **eating plenty of fruit and vegetables (including legumes)**
- **eating plenty of cereals, bread and pasta**
- **eating a diet low in saturated fats**
- **choosing foods low in salt and use salt sparingly**
- **including foods high in calcium, and**
- **using added sugar in moderation.**

For people with dementia maintaining good nutrition can present extra challenges. They may:

- **suffer from a loss of appetite**
- **develop an insatiable appetite or a craving for sweets**
- **forget how to chew or swallow**
- **suffer from a dry mouth or mouth discomfort, and**
- **not recognise the food or drink given.**

TIPS FOR CARING

- **Meals should be used as shared social occasions whenever possible.**
- **Stock up on healthy snacks such as yoghurt, cheese or dried fruit that do not need preparation or cooking.**
- **Prepare a plate of nutritious food that can be picked up in the fingers.**
- **Do not use complicated table settings.**
- **Assist with the cutting of food but avoid assisting the person to eat unless absolutely necessary.**
- **Allow time for the memory to respond to food.**
- **Serve only one plate of food at a time.**
- **Reduce distractions at mealtime.**
- **If the person is not eating, investigate possible causes such as depression or problems with gums, teeth or dentures.**

Intimacy and sexual issues

The need for closeness is a very important and natural part of everyone's lives. People with dementia continue to need caring, safe relationships and touch. Basic intimacy needs do not disappear just because the person has dementia.

Some people with dementia may experience an increased interest in sex while others may show no interest at all. Sometimes inhibitions are lost and the person may make inappropriate advances to others or undress or fondle themselves in public.

TIPS FOR CARING

- If sexually inappropriate behaviour occurs, remain calm and don't take offence.
- Look for reasons behind the inappropriate behaviour. For example, the person may be removing their clothes because they want to go to sleep or to the bathroom.
- Try to redirect the person to another activity such as their favourite food or a walk outside. If in public, take them to a quiet area and dress them again if necessary.
- Find ways to include different forms of touch in the everyday routine so that the person receives physical contact – massage, holding hands and embracing are ways of continuing to provide a loving touch.

Continence

Continence is the ability to control bladder and/or bowel function. Incontinence is the loss of this ability, which is often very distressing for those affected, and their carers. There are many things that can be done to ensure maximum comfort and dignity.

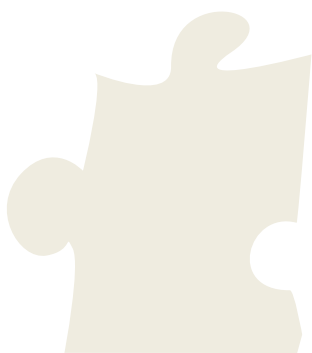
Make sure that a medical assessment is carried out to rule out treatable causes such as constipation, urinary tract infection or diabetes.

Changes in the brain that occur with dementia can interfere with a person's ability to:

- recognise the need to go to the toilet
- be able to wait until it is appropriate to go to the toilet
- find the toilet
- recognise the toilet, and
- use the toilet properly.

TIPS FOR CARING

- Be sure that the person is drinking enough fluids throughout the day (5-8 glasses daily) to keep the bladder healthy and prevent urinary tract infections. (Jelly, ice cream or custard may be substituted).
- Consider limiting caffeine intake as it can irritate the bladder and increase the need to urinate.
- Encourage using the toilet before and after meals, before bed and on waking.
- Use clothes that can be easily removed such as an elastic waist on trousers and loose fitting dresses and under garments.
- Place signs leading to the toilet and fix a picture on the toilet door as a further cue.
- Make sure that there is good night lighting so that the toilet can be found easily.
- Absorbent pads, and absorbent sheets and waterproof underlays on chairs and the bed will help to reduce laundry. Incontinence pads are available through the Department of Veterans' Affairs Rehabilitation Appliances Program (RAP).
- The National Toilet Map may help you plan ahead for toilet breaks when travelling. Visit www.toiletmap.gov.au



Sleeping

Sleeping problems are common for people with dementia. Their sleeping habits may change so that they sleep during the day and stay awake at night. Many will need less sleep as they do less during the day.

TIPS FOR CARING

- It can be helpful to keep a diary to see if a pattern of behaviour is developing.
- Plan activities during the day so that the person avoids sleeping for long periods.
- Make sure that the bedroom is comfortable, warm and adequately lit.
- Ensure the person is able to find the toilet at night. Consider using a night-light.
- Have set, regular times for bed.
- Try a light snack, herbal tea or warm milk before bed.
- Provide soothing music or read to the person before bed.
- Cut down on alcohol and caffeine during the day.
- Discuss sleeping problems with your doctor. Stopping or changing medications may be contributing to the problem. The doctor can also arrange a medical check-up to identify and treat any physical ailments, or any side effects of medications.
- Depression can cause problems with sleeping. Ask your doctor if an assessment is necessary.

Wandering

Wandering is quite common among people with dementia and can be very worrying for families and carers concerned about their safety and wellbeing.

People may wander for a number of reasons. They may feel disoriented in a new environment or they may just forget where they were going or why. Wandering can also be a way of using up excess energy or the result of boredom or of being upset.

TIPS FOR CARING

- It can help to look for a reason for the wandering.
- Talk to the person's doctor about whether any illness or pain, or the side effects of medication might be triggering wandering.
- Increased exercise, such as walking, may help reduce the desire to wander.
- Provide diversional activities, such as music or gardening.
- Remove cues associated with going out, like house keys and money.
- Place stop signs at exit doors or black strips across doorways.
- Install bells and buzzers that sound when external doors are opened and lock gates. Move keys to the door locks where the person will not think to look for them.
- Make sure that the person carries some form of identification in case they get lost. An identity bracelet with a name, address and telephone number or a Medic Alert bracelet is useful. It may be helpful to sew a nametag into garments the person wears regularly.



Aggression

Some people with dementia may exhibit physical and verbal aggressive behaviours such as hitting and excessive swearing.

TIPS FOR CARING

- Exercise may help reduce some outbursts.
- Try to anticipate the person's needs to avoid frustrating them.
- Always explain what you are going to do in case they feel threatened by your actions.
- A familiar routine and a calm environment may help avoid some behaviours of concern.
- If behaviour becomes aggressive, it is usually best not to make physical contact. It may be better to leave them alone.
- Speak in a calm, reassuring voice.
Do not be drawn into an argument.
- Do not punish them for their behaviour.

Hallucinations, delusions and paranoia

Brain changes in dementia can cause the person to suffer altered experiences. Hallucinations are sensory experiences that cannot be verified by anyone else. Typically the person sees or hears something that is not there and this can be frightening for them.

Delusions are ideas not based on reality, but which the person with dementia believes to be true. Common delusions include ideas that people are stealing from them or are intending to harm them.

Paranoia is characterised by unrealistic beliefs. These are usually beliefs of either persecution or grandeur. Sometimes the person may become very suspicious, accusing others of stealing, hiding their belongings or accusing their partner of being unfaithful. They may also believe that they possess superhuman powers.

TIPS FOR CARING

- Do not argue. It is better to acknowledge that the delusions and hallucinations frighten the person. Allow them to discuss their concerns.
- Investigate suspicions to check their accuracy.
- Try activities that may distract them.
- Try to maintain a familiar environment, including consistent routines, and if possible, familiar carers.
- Medication can sometimes help to control delusions and hallucinations in people with dementia.
- Arrange for a medical check-up to eliminate the presence of other physical or psychiatric problems and to check the effects of medication.

Depression

Depression is a feeling of extreme sadness and is very common among people with dementia. Some of the typical signs of depression are a loss of interest in activities that were previously enjoyed, lack of energy, poor sleep and feeling worthless.

It can be difficult to tell the difference between dementia and depression, as many of the symptoms are alike. However, treating depression can make significant improvements so it is very important that it is investigated and treated.



TIPS FOR CARING

- **Be positive.** Frequent praise will help the person feel better.
- **Be realistic** about what the person can do.
- **Try to keep to a daily routine.**
- **Limit the amount of noise and activity in the environment.** This may help avoid over-stimulation.
- **Discuss the person's symptoms with their doctor.**
- **Medication such as anti-depressants may be prescribed.** These can be very helpful, but can have side effects for people with dementia. These should be discussed with the doctor before treatment commences.