

Later stage Alzheimer's disease: A guide for the carer

Caring for a person with Alzheimer's disease is certainly not easy, particularly as they begin to progress to the later stages of the disease, but there are steps you can take to make things easier.

This guide is a compilation of tips and advice aimed to address the practical care issues faced by those looking after people with Alzheimer's disease.

Throughout this booklet, the emphasis is on helping the carer to work with the person with Alzheimer's disease to find a balance between good care, mutual respect, and continued independence to the highest degree possible.

It is strongly recommended that carers seek further assistance, if necessary, from local and national Alzheimer's disease and Carer organisations, as well as from their doctor and local community. Please refer to the back page of this booklet for further contact details.

Remember that this is general information only. Many of the issues raised may not be relevant for you, or arise after the disease has progressed for some time.

Coping with memory loss

Memory problems are often the first symptom of Alzheimer's disease to appear, and they get progressively worse as the disease becomes more severe.

There are some simple techniques that can be used to overcome the practical issues associated with memory loss, and as someone enters late stage Alzheimer's disease these might become more helpful.

- **Use reminders** such as lists, notes, calendars, clocks etc (these may be the only aids needed in the early stages of the illness).

- Don't **argue** with them, contradict them or repeatedly correct them if they have no memory of an event.
- In general, keeping to a regular daily **routine** can help reduce the effect of memory problems.
- **Label** objects around the house and people in photographs, in order to reduce the frustration of not being able to remember a word or name.
- **Label** the doors of rooms with words, as well as pictures, to act as a guide for the person with Alzheimer's disease.

If wandering is a risk, make sure they have **details** of their name, telephone number, address and contact person on them at all times, maybe even sewn into their clothing.



Communicating better

Communication becomes increasingly difficult for a person with Alzheimer's disease, particularly as the illness becomes more severe. It is difficult for them as they can no longer remember the right words to use or the appropriate response to give.

A carer must learn new ways of responding to changed behaviour and adapt their methods of communication accordingly.

The suggestions below may help to communicate more effectively:

- Keep sentences **simple**, not giving too much information at once.
- Give the person **time** to respond to you.
- **Listen** carefully to what the person is saying. Make eye contact and use positive body language. Always reply clearly and calmly, and make sure that competing noises, such as TV or radio, are limited.
- Be **reassuring** and use humour if appropriate. This can often be helpful in relieving tension.
- If they cannot remember day-to-day events, try discussing memories from **the past** – these are frequently easier for the person to remember, and can bring back happy thoughts.
- If the person seems to be struggling to communicate a thought, gently try to **offer** the word he or she may be looking for.
- Keep communicating, even if there is no answer.

Sense the change

People with late-stage Alzheimer's experience the world through their senses, so use their senses to maintain a connection:

- **Touch** – hold their hand
- **Smell** – wear their favourite perfume
- **Vision** – watch their favourite videos with them
- **Hearing** – read to them



Living with Alzheimer's disease

Around the house

A diagnosis of Alzheimer's disease doesn't mean that there has to be a lot of immediate change in the person's home. In fact, keeping things familiar is often the best course of action.

However, when a person begins to progress to the later stages of Alzheimer's disease, alterations may be required to accommodate the fact that they might be less steady on their feet or might be beginning to be more confused about the things around them.

Here are some tips on simple ways in which to accomplish these minor, but important, changes:

- Make the house a safe and **easy** place in which to move around. Avoid too much clutter. As with any home, trailing electrical cords and sharp-edged or unsteady furniture can be hazards.
- Avoid making unnecessary big changes to the home – this can confuse or distress a person with Alzheimer's disease.
- Keep rooms well lit so that all walkways are clearly visible and people can see. Leaving a hall and/or bathroom **light** on at night can also help the person find their way around safely.
- Protect against slippery surfaces, unsecured rugs or uneven steps, which can be potential dangers for those who are unsteady on their feet.
- If stairs are a problem, non-slip strips can be fixed to each step to prevent slipping and reflective or brightly coloured tape can also be useful for marking each step.
- To help with general mobility, devices such as **handrails** can be fitted at useful places around the house and in the bath.

- Put away breakable or dangerous items.
- Keep **duplicates** of necessary items, such as keys, in a safe place.
- Non-hazardous objects that are in regular daily use should be left in obvious, easy-to-reach places.

Help with dressing

For a person with Alzheimer's disease, the process of dressing can become difficult.

It may not only be physically awkward, but they may also lose their understanding of appropriate clothing, and in which order the clothes should be worn.

Here are some ideas to help make dressing easier for both of you:

- Try to establish a specific time each day for the person to get dressed.
- Encourage them to dress themselves, and plan extra time so there's no rush.
- Select clothes with large neck openings, front fastenings, or no fastenings at all.
- Choose clothes with **zippers** instead of buttons.
- It may be possible to add **Velcro®** to existing clothes to make them simpler to fasten.
- Slip-on or Velcro-fastened shoes are easier to put on than complicated lace-ups.
- Choose rubber-soled, non-slip shoes as a safer option for those who are unsteady on their feet.
- Label drawers with **stickers** naming or illustrating the clothes they contain.
- Lay out the clothes in the **order** they are to be put on, or hand clothes to them one at a time.

Some people with later stage Alzheimer's disease have bladder and/or bowel problems (see Page 3 for further information). There are **aids** such as special bed sheets, underpants and pads that are designed specifically to ease some of these problems. In addition, this symptom should be discussed with your doctor.

In the bathroom

Washing and toileting may become increasingly difficult for a person with Alzheimer's disease. In addition to physical problems, they may no longer recognise the need to wash. As a result, bathing may have to be gently encouraged and in such cases it is often helpful to identify the preferences of the person.

Below are some more practical tips related to bathing and toileting:

- There may be a **favourite time** of day, or they may like to associate being washed with preparation for a trip out or visitors arriving.
- For a person who has physical difficulties, there are many **aids** that can be used to help in the bathroom. For example, hand rails, raised toilet seats, non-slip bath and shower mats, and seats designed for use in the bath or shower.
- Make sure that the lock on the bathroom door can be opened from the outside, or even removed, to prevent them being locked in accidentally.
- A person with Alzheimer's disease can find it difficult to judge temperature, so if possible, reset the thermostat of the water heater so that the water never reaches a scalding heat.



Cooking and eating

A person with Alzheimer's disease can change their behaviour when it comes to eating.

They may lose their appetite, or forget if they have already eaten. In addition, it may become physically difficult for them to use knives and forks, or they may not recognise these utensils.

The kitchen can also contain some hazardous equipment, but this doesn't necessarily mean that it should be a restricted area. In fact, cooking may be an activity that you and your loved one can enjoy together.

The following ideas illustrate how the kitchen can be made a safer environment for a person with Alzheimer's disease:

- Use an electric kettle with an automatic 'switch-off' mechanism. This avoids any dangers associated with forgetting to switch the kettle off.
- Have a small household fire extinguisher on hand in the kitchen.
- Lock away sharp objects such as knives.
- Make sure that food is not too hot. A person with Alzheimer's disease is less able to judge the temperature of what they are eating or cooking, and is therefore at greater risk of being scalded.
- When eating becomes more difficult, consider using non-slip mats on the table, a plastic tablecloth, and **bowls** instead of plates.
- If using knives and forks becomes a problem, provide **finger food** as an alternative.
- If they have a lack of appetite, **frequent** small meals or snacks may be more tempting than a routine of two or three larger meals per day.

Activities

Some people with Alzheimer's disease will wander. One good way to minimise wandering is to ensure that the person with Alzheimer's disease is adequately occupied and active during the course of their day.

Some tips regarding activities that will help you to achieve this goal are:

- Find out which activities your loved one enjoys – these can be favourite hobbies, or new activities. For example, gardening, walking, or listening to music.
- Find an activity that can be enjoyed by both yourself and your loved one.
- Make sure that they take regular **exercise**. This is not only healthy but can also reduce the tendency of a person with Alzheimer's disease to wander without cause. Any exercise taken can be combined with a purpose e.g., walking to the shops.
- If appropriate, encourage the reading of books and magazines, and then discuss what they have read.
- Encourage them and **praise** the results of any tasks – whatever the outcome.

Helping with incontinence

As Alzheimer's disease progresses, some people may lose control of their bowels or bladder. This is often a difficult period to manage, and is often one of the reasons families make the decision to place their loved one in full-time care.

There are ways in which incontinence can be managed. Some of these tips might be able to help:

- Take them to the bathroom on a **schedule**. For example, take time out for a bathroom break every three hours.
- Watch for **signs** that they may need to use the bathroom, such as restlessness, or pulling at clothing. Respond as quickly as you can.
- If an accident happens, be **supportive** and **understanding**. Try to keep track of when accidents happen to help plan ways to avoid them.
- Limit fluid intake in the evening to help prevent night time accidents.
- **Plan ahead** for trips outside the home. Have them wear simple, comfortable clothing that's easy to remove, and bring an extra set of clothes in case of an accident.



Changed behaviours

As Alzheimer's disease progresses, the person with Alzheimer's disease experiences changes in personality and they lose the ability to reason logically.

Changes in behaviour can be the most distressing symptoms for carers to cope with, as well as being emotionally stressful.

The tips below can help with working together with your loved one to effectively deal with some of the most common types of changed behaviours:

- In situations of anger, aggression or delusion, don't try to logically reason with them – Alzheimer's disease impairs their logical thought. **Comfort** and **distraction** usually work best.
- Try to **recognise** what triggers certain behaviour, and then try to avoid or minimise these triggers. For example, a noisy environment may confuse a person with Alzheimer's disease, and they respond by becoming distressed.
- **Never punish**, or react angrily to, any behaviour, however aggressive or embarrassing it may be. Such retaliation may cause more fear, confusion or distress.
- Respond to inappropriate behaviour by either leaving the situation to **calm down** for a few minutes, by giving **reassurance**, or by **distracting** them.
- A person with late stage Alzheimer's disease may take to hiding their belongings, or throwing them away, and then forgetting and accusing others of having stolen them. There is always a reason for this behaviour. Try to understand this reason, as it will help you locate the 'stolen' items.
- Always validate the emotions being shown by your loved one.

Remember that it is the illness that is causing the abnormal behaviour, not the person.

Caring for yourself

Practical steps

Caring for another person is an important task and can be all-consuming. It is therefore vital that a carer remembers to look after his or her own needs too.

By dealing with the day-to-day experiences that Alzheimer's disease brings, a carer may have to cope with many physical and emotional challenges. Therefore, every carer is encouraged to learn to recognise their limits and ensure that their quality of life is not suffering unnecessarily.

- **Keep in touch** with family, friends, and the outside world.
- Make time for yourself by arranging regular periods for other carers, family members or friends to share the caring duties.
- **Know your limits** and don't be afraid to ask for and accept for help from family, friends or Alzheimer's disease organisations.
- Join a carer-support group.
- Make sure that you do not perform any physical tasks, such as lifting the person alone – this can cause serious physical damage.
- Regularly visit a **doctor** for your own health checks – especially if you feel particularly tired, depressed or run-down.
- When you need a break, then it is a natural step to arrange for the person to spend time in a respite or residential home. Don't feel guilty about having to make this decision.
- If they are taken into a home, give yourself time to adjust to the change.

Although you will want to make regular visits to the home, try to fit them into your life, rather than fitting your life around the visits.

Emotional needs

- Take time to deal with your own personal needs **without feeling guilty**.
- Accept that your emotions will change frequently, and you will have good days and bad days.
- Don't keep your feelings to yourself. Make sure that you have someone that you can talk to about your emotions and needs – family, friend, or support group.
- **Never blame yourself** for the behaviour of your loved one, or for your reaction towards them. It is no-one's fault.
- Try to avoid taking any anger or accusations personally – the behaviour is not intentional, it is a result of the disease.
- If you feel embarrassed about the public behaviour or condition of your loved one, then explain the situation to those people you see regularly.
- Give yourself praise for your achievements in care-giving.



Managing financial and legal matters

Although it may not be the obvious reaction to a diagnosis of Alzheimer's disease, financial and legal affairs are some of the first matters that need to be taken into hand.

As the disease progresses, your loved one with Alzheimer's disease will eventually become unable to control their own legal and financial affairs. This can cause many problems.

However, there are several ways in which future decisions can be safely arranged in advance. If this is done promptly, then your loved one will be able to make their own wishes known, and make sure that their future life and care will proceed in the way that they choose. As a result, the family and carers of any person with Alzheimer's disease will have an enormous burden lifted.

Finances

When a person is first diagnosed with Alzheimer's disease, it is important to sort out their financial affairs as soon as possible. If finances are well organised at this point, it can prevent difficulties arising when the person reaches the more severe stages of the disease.

Such difficulties may include loss of the ability to deal with payments, savings and other money matters and, if left too late, it may become difficult to legally arrange for another person to take care of these issues.

For all money matters, it is best to get professional advice on the most appropriate schemes and benefits available for the individuals involved. As well as specific financial organisations, it is also useful to speak to someone from a local or national Alzheimer's disease association, who will be able to offer the benefit of their experience in this area.

Suggested financial steps

There are several ways in which a person with Alzheimer's disease can make legal their wishes for when they reach the later stages of the disease.

- Deciding on a Power of Attorney
- Creating a 'living will' which gives healthcare-related instructions such as preference for medication, long-term care choices, as well as more personal care matters such as diet or clothing. This can be a legal document made before your loved-one will become incapable of making these decisions for themselves.
- Set up Trust funds
- Write up a legal will

All of these matters can be taken care of under the instruction of your lawyer, and they can give you advice on which options are best for you and your loved one.

Seeking more information

Alzheimer's Australia National Office

PO Box 108
Higgins ACT 2615
(02) 6254 4233
www.alzheimers.org.au

24hr Dementia Helpline

1800 639 331

State Offices

Australian Capital Territory
(02) 6254 5544

New South Wales
(02) 9805 0100

Northern Territory
(08) 8948 5228

Queensland
(07) 5574 6224

South Australia
(08) 8372 2100

Tasmania
(03) 6278 9897

Victoria
(03) 9815 7800

Western Australia
(08) 9388 2800

There are also many other Alzheimer's and Carer organisations available to help. Please talk to your doctor for more information.

Please consult your doctor for further information.

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