

Frequently Asked Questions about Alzheimer's Disease

1. Who usually cares for people with Alzheimer's disease?

Despite the widespread belief that most people with Alzheimer's disease reside in frail care facilities or nursing homes, families are the primary caregivers for their relatives with Alzheimer's disease.

Within families, care giving is provided most often by wives and husbands, followed by daughters.

2. What types of professionals are available to assist caregivers?

Professionals such as counsellors, psychiatrists, psychologists, social workers, psychiatric nurses, and clergy may be able to provide information. They can also ease care giving burdens or help with specific issues throughout the course of the disease.

A physician may help with health care needs, including management of behavioural symptoms. Select a professional who is familiar with dementia and with whom you feel comfortable.

3. What support services are available for caregivers?

In South Africa - try organisations such as the Mental Health Information Centre tel. (021) 938 9229 or the national office of the Alzheimer's and Related Dementias Association (ARDA), tel. (011) 478-2234/5/6 both of which offer information and publications.

4. How can a caregiver create a safe home environment for someone with Alzheimer's?

Research shows that the physical environment in which the person with Alzheimer's disease lives can be important for stimulating cognitive functioning, promoting independence, improving safety, managing behaviours, and reducing stress and anxiety.

Creating a safe living environment can be important in preventing many stressful and dangerous situations.

If the person begins to wander, consider installing secure locks on all outside windows and doors and removing locks on bathroom doors to prevent the person from locking him or herself in. Medications should be labelled and locked up.

Knives, lighters, matches, and guns should be secured out of reach. Keep the house free of clutter and remove scatter rugs and anything else that might contribute to a fall. Childproof latches on kitchen cabinets or any place where chemicals or cleaning supplies are kept also may be used.

5. What kinds of behaviours does a person with Alzheimer's exhibit?

Alzheimer's is a progressive disease -- the symptoms grow worse over time. Yet, it is also a variable disease. Symptoms progress at different rates and in different patterns. The appearance and progression of symptoms will vary from one person to the next.

The behaviours a person exhibits will be based on how advanced the disease is and the particular way he or she is affected.

Symptoms will likely include confusion, memory loss, and problems with routine tasks. The person may also experience anxiety, sleep disturbances, and difficulty recognizing family and friends, among a variety of other symptoms.

Sometimes the person with Alzheimer's disease may exhibit violent behaviours, wandering, restlessness, and/or inappropriate social or sexual behaviour. Not all people experience all of these problems, and the intensity and duration of the behaviours may vary. Most of these behaviours, if they occur, happen in the middle stages of the disease, and can often be helped with medication or behavioural interventions.

6. How is Alzheimer's disease treated?

No treatment is yet available that can stop Alzheimer's disease. However, for some people in the early and middle stages of the disease, the drugs Cognex®, Aricept®, Exelon®, or Razadyne® may help prevent some symptoms from becoming worse for a limited time.

Also, some medicines may help control behavioural symptoms of Alzheimer's disease such as sleeplessness, agitation, wandering, anxiety, and depression. Treating these symptoms often makes people with Alzheimer's more comfortable and makes their care easier.

7. How do vision problems affect the behaviour of someone with Alzheimer's?

Many, but not all, people with Alzheimer's disease develop vision problems. Most often vision problems occur in visual-spatial functioning. This means that they may have trouble with bumping into things, finding common objects, finding their way in their surroundings, reading, or performing fine hand-eye coordination activities such as brushing their teeth.

Modifying the environment often can help people with Alzheimer's disease cope with vision problems. Enlarging markings on appliances, including the numerals on the telephone, and using higher wattage light bulbs to increase lighting are ways to assist people experiencing vision problems.

8. How does the time of day affect the behaviour of someone with Alzheimer's?

The symptoms of many people with Alzheimer's disease tend to worsen in the evening. This is often referred to as "sun-downing." Making sure that the person has adequate rest and a calm, comfortable, and well-lit.

9. What activities might interest a person with Alzheimer's disease?

First of all, do not expect too much. Finding activities that a person with Alzheimer's disease can do and is interested in can be a challenge.

Simple activities are the best, especially if you can find activities that use the abilities the person has retained.

Activities that are familiar, such as folding clothes, kneading dough, or digging in the garden may be comfortable.

Think of other opportunities for pleasant events, such as bringing in live pets or stuffed animals, playing calming music, or growing a garden.

Help the person to get started on an activity and break the activity down into small steps. Give praise for each step completed. Try to incorporate activities into a normal daily routine.

10. What types of exercise should a person with Alzheimer's engage in?

Choose exercises that both you and the person find easy and can do together. Physical activities you both enjoy, perhaps walking, swimming, tennis, dancing, or gardening might be good choices. Check out local exercise programs such as classes at senior centres or simply take a walk through a shopping mall. Build slowly and be realistic in your expectations.

11. What is the best way to communicate with a person who has Alzheimer's?

People with Alzheimer's often have problems expressing themselves and understanding others when they speak. When the person is talking, listen carefully, observe body language, and eliminate distractions such as radio and TV.

It is best to address the person in a calm, gentle tone of voice and use simple words and short sentences. You may need to repeat yourself several times or use hand gestures to show what you mean.

13. What are ways to ensure that a person with Alzheimer's eats properly?

It is helpful to make meals as simple as possible. Avoid serving too many different kinds of food on one plate. If meat is served, cut it into small pieces. Soft foods like apple sauce, yoghurt, eggs, and creamed cereals may be easier for the person to eat.

14. What role does nutrition play in Alzheimer's disease?

While there is no scientific evidence of a dietary cause of Alzheimer's disease, research has shown that vitamin E can slow the progress of some consequences of Alzheimer's disease by about 7 months. There is no reliable evidence, however, that other vitamins or nutrients can stop, reverse, slow, or prevent Alzheimer's disease.

Yet, a healthy diet is important for people with Alzheimer's disease. Poor nutrition can result in either weight loss or weight gain, and may contribute to other problems such as high blood pressure, listlessness, fatigue, dental problems, or loss of bladder or bowel control.

Some of the symptoms of Alzheimer's disease can be mimicked by vitamin B12 deficiency. This nutrient deficiency is a reversible cause of dementia, along with thiamine deficiency, thyroid hormone deficiency, certain medications, and metabolic disturbances. Reversible causes of dementia need to be excluded before a presumptive diagnosis of Alzheimer's disease is made.

15. How should a caregiver handle bathing a person with Alzheimer's?

The caregiver should draw the person's bath and should adjust the water temperature to avoid scalding. The room should be warm and free of scatter rugs, and the bathtub should have non-skid coverings.

A hand-held showerhead on a flexible cable can help with washing, and a shower or tub bench and grab bars can prevent slipping. Also, make sure that there are enough towels to quickly dry the person, preserve their dignity, and keep them warm.

16. How can a caregiver help a person with Alzheimer's get dressed?

Encourage the person to dress him or herself to whatever degree possible. To reduce confusion, allow the person to choose what he or she will wear from a limited selection of outfits. If he or she has a favourite outfit, consider buying several identical sets.

Arrange the clothes in the order they are to be put on to help the person move through the process. Choose clothing that is comfortable, easy to get on and off, and easy to care for. Elastic waists and Velcro enclosures minimize struggles with buttons and zippers.

17. What is the best way for a person with Alzheimer's to get a good night's sleep?

It is important to set up a regular schedule for a person with Alzheimer's disease that includes adequate rest. Encourage exercise during the day and limit daytime napping. Restrict the person's access to caffeine late in the day and consider developing a bedtime routine.

18. What steps should a caregiver take when the person with Alzheimer's becomes incontinent?

It is important to have a routine for taking the person to the bathroom and to stick to it as closely as possible. A good rule of thumb is to plan to take the person to the bathroom every 2 to 3 hours during the day. Don't wait for the person to ask.

19. What should a caregiver do when the person with Alzheimer's becomes incompetent to drive?

If you observe incidents of poor judgment, risk-taking, and/or dangerous behaviour at the wheel, take steps to stop the person from driving.

A variety of options are available to stop someone from driving. The caregiver can ask for a doctor's help, hide the car keys, hide or even disable the car, or use a combination of these approaches to ensure that the person stops driving. Safety must be the first priority.

20. What is the best way to cope with holidays?

Holidays are bittersweet for many caregivers. The happy memories of the past contrast with the difficulties of the present and extra demands on time and energy can seem overwhelming. During these times, it is important to find a balance between rest and activity.

Include the person as much as possible in important family traditions and encourage family and friends to visit. However, it is a good idea to limit the number of visitors at any one time and to schedule visits during the time of day when the person is at his or her best. Avoid crowds, changes in routine and strange surroundings that may cause confusion or agitation.

21. What is the best way to handle visits to the doctor?

It is important that the person with Alzheimer's receive regular medical care. Advance planning can help the trip to the doctor's office go more smoothly.

Try to schedule the appointment for the person's best time of day. Let the doctor's rooms know in advance that this person is confused. There may be something they can do to make the visit go more smoothly.

Don't tell the person about the appointment until the day of the visit or even shortly before it is time to go. Bring along something to eat and drink and any activity that he or she may enjoy. If possible, have a friend or another family member accompany you so that one of you can be with the person while the other speaks with the doctor.

22. How can a caregiver handle wandering?

Wandering and restlessness are common symptoms of Alzheimer's disease, especially in the moderate and severe stages of the disease.

It may be helpful to keep a regular daytime routine that includes activity and exercise. Some caregivers find it helpful to use nightlights, bells on doors, or locks placed in an unaccustomed position at the bottom of the door to prevent wandering.

It is often helpful to have a bracelet made for the person to wear for identification purposes. Keep recent photographs of the person available at all times. Include brightly coloured items of clothing in the wardrobe. Place identification on shoes, eyeglasses, purse or wallet, and keys.

23. How should a caregiver respond when a person with Alzheimer's experiences hallucinations and delusions?

A person in later stages of Alzheimer's disease may suffer from hallucinations or delusions. Hallucinations occur when the person sees, hears, smells, tastes, or feels something that is not there. Delusions are false beliefs that the person cannot be dissuaded of.

Arguing with the person is ineffective, and it may increase his or her agitation. Calm reassurance is the best approach.

Sometimes moving to another room or going outside for a walk may help. Make sure the person is safe and does not have access to anything he or she could use to harm anyone.

24. What are some signs of caregiver stress?

Some warning signs of caregiver stress are feeling sad or depressed, lying awake and crying, losing weight, feeling isolated or alone, and feeling more angry or frustrated with one's situation and with the need to provide care.

It is important for caregivers not to ignore their own physical health symptoms and conditions. They should visit the doctor regularly for their own health care needs before conditions get worse.

25. How can caregivers make sure they take care of themselves?

Caregivers need time away from stress to maintain their own health, and they should have some time to themselves every day. Adult day care and respite care are beneficial for the person as well as the caregiver, providing structure, activities, and opportunities for socialization.

It is important for caregivers not to ignore their own health. They should visit the doctor regularly for their own health care needs before conditions get exacerbated.

26. When is the right time to place a person with Alzheimer's disease in residential care?

There is no definite rule regarding the right time to place a person with Alzheimer's disease in a more protective or specialised environment.

This decision requires careful consideration by the caregiver of the person's needs and the caregiver's ability to manage the person's care safely. Consultations with professionals can be helpful in making this decision.

27. What major factors should be considered when choosing a residential care facility?

The major factors to consider in a frail care facility include experience and expertise of the staff and administration, quality of recreational and therapeutic activities, location, and cost.