

Caring for someone with dementia

The information you can find here is taken from the Care Manual project which was financed by the European Commission. The information in the Care Manual is the result of Alzheimer Europe's member associations having shared their knowledge and experience of caring for a person with *dementia*.

This aim of this project was to provide general information about Alzheimer's disease and other forms of dementia and to provide useful tips and hints for carers of people with dementia. This section offers practical solutions to the problems that carers may face. Some of you may have just learned that a loved one has Alzheimer's disease or another form of dementia. You and other members of your family, together with the person with dementia, may be faced with new situations and challenges. Although this can sometimes be stressful, with appropriate information and timely support, you can do a lot to maintain the quality of life of the person you are caring for, and at the same time look after yourself, which is equally important.

This section describes situations which carers quite often encounter. However, we have covered numerous issues, many of which you will probably never encounter. So please, don't be disheartened.

As dementia develops gradually over time and so too do the needs of the person with dementia, a particular solution may be helpful for a time but you may eventually need to try a different approach. You may sometimes feel alone with your problems and worry about how you will cope. You might find it helpful to talk to someone who is or has been in a similar situation to you, or you may want to obtain information about possible support. Alzheimer Associations are there to help you and most can provide you with the opportunity to meet other carers. They can also provide you with support and information about care, as well as about administrative and legal matters. Contact details of national Alzheimer associations can be found on this website in the section "About us".

How to use reading, writing and pictures/symbols

You may have found that the person with dementia sometimes understands a written message, but has difficulty understanding what you say or can read something correctly without understanding the meaning. You may have been surprised to find that they can sign their name long after they have lost the ability to write. Many people understand pictures and symbols, although the same symbol might not be as effective for different people. These different forms of communication all involve different skills and abilities, which may change over time and are different for different people. It is important to make the most of different forms of communication for as long as they are effective.

How to make the most of reading, writing and pictures/symbols

Strategically placed self-adhesive stickers, sheets of paper, white wipe clean slates and small blackboards are all useful means to leave messages, e.g. “Don’t forget to lock the door”. In order to avoid confusion, it is best to leave two notes rather than put two messages on the same note and not to have too many notes. The person’s abilities are likely to change over time so it would be a good idea to occasionally check that the person with *dementia* can still read and that they understand what the words mean. You could also label drawers, cupboards and doors to indicate what they contain e.g. socks, food cupboard or which room they lead to, e.g. bathroom or kitchen. Such labels could be combined with images (e.g. symbols, photos or drawings etc.). For example, on the toilet door you could have a picture or symbolic representation of a toilet with the word “toilet” written below. This can be particularly helpful in situations where there are several people with dementia living together. However, it is important to remember that some symbols might be too abstract to be useful. It is therefore best to avoid modern looking abstract symbols or pictograms as people with dementia may have difficulty interpreting them.

How to prevent problems due to memory loss

A stable environment and routines

As people with dementia lose the ability to learn due to memory loss, it is best to adapt the situation or surroundings to their needs, rather than trying to teach them how to adapt to their own changing abilities. For example, if the person with dementia tends to forget to turn off the tap, you could perhaps have a device fitted which allows only a certain amount of water to come out at any one time. However, try to keep changes to the minimum and concentrate on creating a stable environment that the person can count on.

Daily routines can also help the person to cope. It might sound monotonous to always do things in the same order, but for someone with dementia this can help prevent anxiety, avoid confusion and help the person to concentrate their time and efforts on other things.

Information on memory loss in particular situations

Many problems encountered by people with **dementia** are linked to **memory** loss in some way, e.g. forgetting to wash, to eat, how to get dressed, where the toilet is, etc. For this reason, they are dealt with in detail in the following chapters (i.e. on personal hygiene, eating and drinking and **incontinence**, etc.).

How to prevent problems due to disorientation

Create routines

As it becomes increasingly difficult for the person with dementia to keep track of time, it helps if you stick to a regular routine with several events to break up the day, thereby providing some kind of structure. If there are enough events occurring throughout the day, there are more opportunities to realise roughly what time of the day it is and even what is going on. A regular routine prevents the day seeming like a continuous series of surprise events and this may reduce anxiety. One idea is to write down a plan of the day's routine at breakfast time with the person with dementia. You could then go over it again at lunchtime. Otherwise, you could stick to more or less the same basic routine every day, without actually writing it down.

Adapt and then maintain a stable environment

It is a good idea to try to maintain a stable environment, always putting things in the same place and not making too many drastic changes. Fitting signs on doors with either a picture or words may help the person with *dementia* to get around their home, even when it no longer seems like a familiar place. (Please refer to the chapter on communication for guidelines on using signs.) This will not relieve them of the feeling of being lost or in the wrong place, but it will help to reduce the *anxiety* caused by not knowing their way round. Labels or signs on cupboards and drawers can help someone with dementia to find their way around without having to ask and draw attention to the problem.

Moving the person with dementia from one place to another is likely to increase *disorientation*. Therefore, if other family members share the caring, it is better for them to visit, rather than move the person with dementia from one home to another in rotation. The more familiar the surroundings, the easier it is for the person with dementia to feel at home and comfortable. On the other hand, as long as the person has confidence in the family or in another person, there should not be a problem taking care of them in another place, e.g. a day care centre.