

Help for carers of a person with dementia

The personal and emotional stress of caregiving and looking after yourself

Alzheimer's disease not only affects the person with dementia, it affects the entire family. The greatest burden is placed on the caregiver. The personal and emotional stress of caring for a person with dementia are enormous and you need to plan ways of coping with the disease for the future. Understanding your emotions will help you successfully cope with the person's problems as well as your own. You are an important person in the life of the person with dementia. Without you the person would be lost. This is why it is essential to take care of yourself.

Here we look more closely at your emotions and needs as a carer. The topics we will talk about include:

Grief

"Try to accept that feelings of grief are a natural response to the situation."

Because of Alzheimer's disease, you may feel that you have lost a companion, friend or parent, and grieve for the way they used to be. Many caregivers find themselves shifting between hope and despair, thinking the person may get better, then knowing they will not. Also, because dementia is progressive, just when you think you have adjusted, the person may change again. It may be devastating when the person no longer recognises you.

Try to focus on what makes life as pleasant as possible for you both, and look for the parts of the person's personality that still remain.

It is important that you find someone to talk to. Sharing your feelings with family, friends and other caregivers is one way of coping with the grief. Many caregivers have found that joining support groups is a good way to get encouragement and assistance to keep going.

Guilt

"It is common to feel guilty."

It is common to feel guilty for being embarrassed at the person's behaviour, for anger at the person, or for feeling that you can not carry on and are thinking about nursing home placement.

The decision to move someone you care about or love into a nursing home is a difficult and painful decision to make. Yet caring for someone with dementia can become a 24-hour occupation and there comes a time when short breaks of respite care will not provide sufficient relief. Eventually, you risk damaging your own health if you do not consider moving the person to a home, where they can get the 24-hour help they need. You may find it helpful to talk to other caregivers and friends about the feelings of guilt. Just because the person you are care for goes to a nursing home, it does not mean giving

up your caregiver responsibilities. Indeed the care home may be grateful for your help at mealtimes or with bathing. Continuing to help in this way will help relieve your feelings of guilt.

Anger

"Getting angry is normal."

It is important to remember that you are not perfect. It is normal for you to lose your temper and get angry at times - as do all other caregivers. Your anger may be mixed. It may be directed at the person, yourself, the doctor, or the situation, depending on the circumstances. It is important to distinguish between your anger at the person's behaviour, resulting from the disease, and your anger with the person, as this will help you to cope better.

Try to understand the person's behaviour that is upsetting you and see if you can stop or reduce it, as it will not help either of you to lose your temper. If you think you are going to lose your temper, go into another room or into the garden and give vent to your feelings away from the person with dementia.

It may be helpful to seek advice from friends, family, or a support group. Sometimes people feel so angry that they are in danger of hurting the person they care for - if you feel like this, you must seek professional help. Many local support groups have caregivers' contacts, with whom you can talk to and get advice from. Use these people to get help when you need it.

Embarrassment

"Ease any embarrassment by taking the courage to explain the situation to people around you."

You may feel embarrassed when the person displays inappropriate behaviour in public or disrupts the neighbours. It may take some courage, but by explaining the disease and the concept of dementia to friends and neighbours, you will help them understand the person's behaviour.

Look for support from other caregivers who have experience of similar problems. Sharing your feelings with other caregivers will enable you to cope better and the embarrassment may fade.

Loneliness

"Try to maintain friendships and keep social contacts, as loneliness makes caregiving harder."

Many caregivers withdraw from society and, along with the person with dementia, are confined to and around their homes. Being a caregiver can be lonely - you may have lost the companionship of the person, as well as social contacts, due to the demands of being a caregiver.

Loneliness makes coping with the problems of caregiving harder, so try to keep in contact with friends, and see if they can offer extra help. Explain the problems of

dementia and that they, as friends, can help by providing you, or the person with dementia, some companionship.

Maintain your own social engagements and take breaks from looking after the person. This will give you time and space to recharge your batteries and help you feel better about yourself.

Consider joining a support group. Here you will find people with similar problems, who can help you get over the rough patches and provide a social life, where you do not have to be separated from the person you are caring for.

Family support

"The family can be the greatest source of help."

For some caregivers their immediate family is the greatest source of help. For others it is the biggest source of distress. If this is the case, you may feel that you have been left to cope as a caregiver on your own, which can lead to bitterness and resentment. If you are feeling distressed because family members are not supporting you, try to find out why they are not helping. It may be helpful to call a family meeting to discuss the care of the person.

If you cannot get help from your immediate family then try to get help from elsewhere. Accept help from other family members and do not take on the burden of caring alone. Try to arrange breaks from caring to give you the respite care you need. You may find that by looking after yourself, you feel less stressed about the lack of family support.

Sharing problems

"Share your problems."

You need to share your feelings about your caregiving experiences with others. If you keep them to yourself, it may be more difficult for you to look after the person with dementia, as you may begin to resent them or get angry with them. Try to think ahead and have someone to turn to in an emergency.

You will most likely find that your friends have not stopped liking or caring about you, and would probably be quite happy to listen or help if you let them know how. Try to accept support when others offer it, even if you do feel you are troubling them.

If you can realise that the problems and feelings you are experiencing are a natural response to your situation, it will be easier for you to cope. If you do not want to bother your friends then seek professional help from the person's doctor or the local support group.

Taking time-out

"Make time for yourself."

It is essential to make time for yourself. As a caregiver you risk isolation by looking after someone with dementia. This can cause loneliness and sometimes anger or resentment

towards the person with dementia. Taking time-out allows you to spend time with others. Enjoy your favourite hobbies and, most importantly, enjoy yourself. Support groups, social services and some nursing homes provide day care help, where you can leave the person with dementia in safety and comfort while you can enjoy time to yourself or with the rest of your family. Use the support available to you, so that you can have a rest.

Know your limits

"Be aware of how much you can take, and seek help if caring becomes too much for you."

How much can you take before it becomes too much? Looking after someone with dementia is a demanding role, which may be complicated by:

- your own physical or health problems
- lack of sleep
- financial uncertainty.

Most people will come to realise how much they can take before caring becomes too demanding. If your situation is too much to bear, take action, seek additional support, and call for help to prevent or avoid a crisis.

Not blaming yourself

"Dementia is no one's fault, the disease is the cause."

Do not blame yourself or the person with dementia for the problems you encounter. This is particularly hard if the person cannot remember who you are or if they are violent. Remember the disease is the cause not the person.

If you feel your relationships with friends and family are fading, don't blame them or yourself. Try to find what is causing the breakdown and discuss it with your friends and family. These relationships can be a valuable source of support for you and the person with dementia.

Seeking and taking advice

"Learning to seek and take advice can help you be a better caregiver."

Learning to accept help may be new to you. More often than not, family, friends and neighbours may want to do something to help you and the person with dementia. Self-help groups (a group for caregivers) can be another source of help for you. They provide an opportunity to get together with other helpers and caregivers, who may already have experienced the problems you are facing. Through their combined

experience, these groups can be an invaluable source of help, comfort and encouragement.

Your doctor, community nurse or social worker may also be able to help you. They will be able to provide you with help and advice about looking after the person and the support available. If they cannot answer your problems themselves, they will usually be able to put you in contact with someone who can.

Source : <http://www.alz.co.uk/carers/yourself.html>