

Feelings of guilt

When caring for a person with dementia you may feel guilty even when you are doing the best you can. Such feelings, which are very common among carers, may undermine your confidence and self-esteem and make it harder for you to cope. If you can understand more about why you are feeling guilty you may be able to find ways to handle the situation.

There are many different reasons why carers feel guilty. Perhaps these feelings arise from your past relationship with the person who now has dementia, or perhaps they are triggered by a particular situation. Perhaps you are simply expecting too much from yourself. If you can work out why you are feeling guilty and talk it over with someone who understands, you may be less inclined to blame yourself. You will then be able to think of positive ways forward.

Possible reasons for guilt and suggestions for coping

Mistakes

Carers often feel guilty about the occasional oversight or error of judgement. You may need to be reassured that it is all right to make mistakes. No one can get it right all the time. Try to focus on the many things that you do well in caring.

Unrealistic expectations

You may feel guilty because you have somehow failed to match up to your own expectations or the expectations that you believe other people have of you. It is really important to set realistic limits to what you can achieve. Remember that you are a person too and entitled to have a life of your own.

Unpleasant thoughts and feelings

You may feel ashamed of being embarrassed or disgusted by the behaviour of the person with dementia despite understanding that they cannot help it.

You may feel guilty because you sometimes want to walk away from your responsibilities or you may sometimes wish the person was dead.

You need to accept that most carers have experienced similar thoughts and feelings and that, in the circumstances, they are quite normal. It may help you to talk them through with an understanding professional, in a support group or with a good friend.

Feelings about the past

It may be that the person who now has dementia used to criticise you in the past or always made you feel inadequate. This may mean that even now you feel uneasy and afraid that nothing you do can be right. You might feel guilty that you never liked the person and they now seem so helpless. Or you may wish that you had previously made more effort with the relationship.

Some people who feel this way are tempted to push themselves too hard in an attempt to compensate for the past. Try to come to terms with what happened in the past, so that you can leave it behind and deal with the present and future.

Expressing irritation or anger

You may find it hard to forgive yourself for occasionally showing your irritation or anger. Don't blame yourself. Accept that you are living with a high level of stress. You need an outlet for your emotions, time to yourself and support. Cry/laugh with another person that you are close to.

Look for ways of expressing natural feelings of frustration safely away from the person with dementia . such as finding the space and time to have a good shout or to punch a cushion. These techniques help to relieve tension by allowing you to express your pent-up negative feelings. Take advantage of any offers of help so that you are able to relax and unwind away from the person you are looking after.

If however you feel that you cannot trust yourself to refrain from physically slapping or hurting your patient, call for help immediately.

Worries about dementia

You may worry that somehow you may have caused the person's dementia. Doctors and other professionals will be able to reassure you that the dementia was not caused by anything you said or did.

You may also feel it is your fault if the person behaves in certain ways . such as constantly walking about or seeming very agitated or distressed. You need to accept that these types of behaviour are associated with the dementia.

Do your best to provide calm, relaxed, routine to help the person feel more secure. But accept that it is impossible to anticipate another person's behaviour all the time. Accept yourself first.

Accepting help

Many carers feel that they should be able to manage without any help. You may worry that the person with dementia will be distressed if you are not there all the time.

Looking after a person with dementia 24 hours per day for 365 days a year is exhausting. Accepting help means that you will have more energy and that you may be able to go on giving quality care for longer. Even if the person with dementia is upset at first about others becoming involved they will eventually get used to the idea and come to accept it.

Respite care, as it is known, comes in the form of help in the home, day care and residential respite care. It is usual for the carer to find that the first experience of separation makes them feel guilty and they are unable to relax.

But do not be put off. You will both get used to the separation and you will gradually experience the benefits of respite, in whatever form it comes. Where possible, let the relief carer spend some time with the patient before you leave them alone together for the first time.

Time for yourself

At first you may feel very guilty about having time to yourself. You may feel that you are being disloyal if you are enjoying things that the person can no longer enjoy. It is important for you to have some life outside caring, to recharge your batteries - you matter too. Combat loneliness . encourage friends and family to visit you.

Conflicting demands

You may feel that you are in a no-winsituation if you are looking after a person with dementia and a family. You may have a job as well. You feel guilty if you are not giving total support to the person with dementia and you feel guilty if you are not giving proper attention to your family or job.

Don't try to meet every demand. You need to work out what are your absolute priorities and how you can meet them. Find out what other forms of support are available.

Feeling trapped

There are some circumstances where people feel particularly trapped. Perhaps their partner developed dementia as they were about to separate. Perhaps the carer wants to continue with a full-time career rather than devote themselves to caring. It is often helpful to talk through these sorts of dilemmas with a person outside the situation such as a friend, community nurse or counselor.

They should be able to help you to reach a decision that feels right for you. Enlarge your conversations beyond just caregiving trials and tips.

Feeling guilty

Celebrate the person's life by focusing on what was achieved in his/her lifetime. Acknowledge yourself and how you made a difference to their lives by caring for them.

Residential care

When the time comes for the person to move to a residential care facility it is very common for carers to feel guilty. You may feel that you have let the person down. Perhaps you feel that you should have coped for longer.

You may have promised them earlier that you would always look after them at home. Now you have been forced to break that promise. It is important to talk this through with someone who understands and who can help you to come to terms with your decision.

Remember that any promises were probably made when neither of you foresaw the possibility of dementia nor fully understood all the strains it might bring. These feelings can persist for a long time and it is a good idea to find a carers'support group where you can talk to other people who have shared similar experiences.

After the person's death

At first you may feel relieved that the person has died. You may then feel ashamed that you have felt this. Relief is a normal reaction. You have probably done a lot of grieving already, as you noticed each small deterioration in the person during their illness.

Notes:

Contact us:

Tel: (021) 421 0077/78
Email: info@dementiasa.org
Or support@dementiasa.org

3rd Floor,
State House,
3 Rose Street,
Cape Town

P.O. Box 16421
Vlaeberg
8018



www.dementiasa.org