

Caring for the Carer

Feelings of guilt

When caring for someone with dementia, you may experience feelings of guilt even when it seems that 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 just why you are feeling guilty, you may be able to find ways to deal with the situation.

There are many different reasons why carers feel guilty. It is important to take time to think about possible causes. Perhaps such feelings arise from your past relationship with the person with dementia, or perhaps they are triggered by a particular situation, or perhaps you simply expect too much from yourself.

If you can work out the reason why you feel guilty and talk this over with someone understanding, you may be less inclined to blame yourself and more 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 judgment. You may need reassurance that it is all right to make mistakes and that no one can get it right all the time. Try to focus on the many things that you do well in the process of caring.

Unrealistic expectations

You may have a sense of guilt because you have somehow failed to live up to your own expectations or the expectations that you believe others have of you. It is important to set realistic limits to what you can do. Remember that you are a person who matters too.

Unpleasant thoughts and feelings

You may feel ashamed of being embarrassed or disgusted by the person's behaviour, although you know they cannot help it. You may also feel guilty because you sometimes wish that you could abandon your responsibility or that your relative was dead.

You need to accept that most carers have experienced similar feelings and that they are quite normal in the circumstances. They do not mean that you are not trying to do your best. It may help to unburden yourself to an understanding professional or a good friend.

Feelings about the past

The person with dementia may have always criticised you or made you feel inadequate, so that even now you feel uneasy, that nothing you are doing can be right. You might feel guilty if you disliked the person because they now seem so helpless, or you may wish that you had made more effort with the relationship in the past.

One temptation to avoid is to push yourself too hard in an attempt to compensate for the past. Try to come to terms with whatever happened so that you can leave it behind and deal with the present situation.

Expressing irritation or anger

You may find it hard to forgive yourself for showing your irritation or anger occasionally. Don't blame yourself. Accept that you are under considerable stress and need an outlet for your emotions, some time to yourself and some support. Look for ways of expressing natural feelings of frustration such as punching a cushion in another room or talking to a friend. Take advantage of any offers of help so that you can avail of any opportunity to relax and unwind.

Worries about dementia

You may worry that some action of yours has caused the dementia. Doctors or other professionals will be able to reassure you that nothing you said or did could have caused the dementia.

You may also feel it is your fault if the person wanders or becomes very distressed, rather than accepting that it is part of the dementia. Provide a calm, relaxed routine to help the person to feel more secure. But accept that it is impossible to anticipate every reaction.

Accepting help

You may feel that you should be able to manage without help as the dementia progresses, or you may worry that the person with dementia will be distressed if you are not there all the time.

Looking after someone with dementia 24 hours a day is completely exhausting. Accepting help means that you will have more energy yourself and may be able to go on caring for longer. Even if the person with dementia is initially upset they will probably get used to the situation and even enjoy having someone else around sometimes.

Time for yourself

You may feel very guilty about having time to yourself or that you are being disloyal if you are enjoying things that the person with dementia can no longer share. But it is important for you to have some life outside caring - you need to recharge your batteries and to realise that you matter too.

Conflicting demands

You may feel that you are in a 'no-win' situation if you are looking after someone with dementia as well as a family or if you have a job. You feel guilty if you cannot give total support to the person with dementia but you also feel guilty if you give less time and attention to your family and work. Don't try to meet every demand. You need to think about how you can meet your absolute priorities and then see what other forms of support are available.

Feeling trapped

There are some circumstances in which people feel particularly trapped. Perhaps their partner developed dementia as they were about to separate, or perhaps they want to continue with a full-time demanding career rather than spend time caring. It is usually helpful to talk through this sort of dilemma with an outside person such as a counsellor who can help you reach a decision that feels right for you.

Residential care

You may feel that you have let the person with dementia down if they have to go into residential or nursing care. Perhaps you feel you should have coped for longer or perhaps you have to break a promise that you would never put them into care. It is important to talk this through with someone who understands and who can help you come to terms with your decision. Remember, any promises were probably made at a time when no one foresaw the possibility of dementia and all the stresses and strains it would bring.

After the person's death

You may feel ashamed because you are relieved when the person dies but this is quite a normal reaction. The person who has died is not the person you have known and you have probably done a great deal of grieving already.

Feelings of guilt arise for many reasons. Try to find someone to talk to - a good friend or an understanding professional - so that you can understand your feelings and make clear decisions about what is right for you and the person with dementia.