

Dealing with guilt

(courtesy of Alzheimer's Society)

If you care for someone with dementia you may sometimes feel guilty, even if others are reassuring you that you are doing the best you can. This sheet looks at some of the issues that can cause carers to feel guilty. It explains why it's important to deal with these feelings, and suggests some ways to go about this.

As a carer, you are likely to feel a wide range of emotional responses to your situation - both positive and negative. This is because although caring can be very rewarding, it is also hard work and can be extremely stressful. Some of the emotions that arise, such as grief and anger, are healthy responses to challenging circumstances. They can be useful, helping us to move forward. But other emotions, such as guilt, can be destructive, leaving us feeling powerless or 'stuck'.

Guilt can be a very tiring emotion, consuming energy that you need for other tasks. If you have feelings of guilt, the first steps to overcoming them are:

- Identifying the feelings of guilt
- Working out where these feelings come from
- Realizing that you are not alone in feeling this way
- Finding ways to develop a more positive attitude of mind and to be more forgiving of yourself

Are you feeling guilty...

... because other carers seem to manage better than you do?

Meeting up with other carers at support groups, or even reading the Alzheimer's Society newsletter, might lead you to believe that other carers are coping much better than you are. You may feel guilty because you feel you haven't matched up to your own expectations, or to the expectations that you believe other people have of you.

Remember that it's alright to make mistakes - no one can get it right all the time. There's no such thing as the 'perfect carer', and it's important not to be too hard on yourself. Are you setting realistic limits to what you can achieve? If not, can you reduce any of the demands you make on yourself or accept any more help?

... because of how you treated the person before they were diagnosed?

Many carers feel bad about how they behaved towards the person before they were diagnosed with dementia. You may have reacted with irritation or criticism, or you may wish that you had made more of the time you spent with the person when they were well.

Try to remember that everyone gets frustrated with their partner or family members from time to time. You weren't to know that they had dementia, and you couldn't have foreseen what the future held. Dementia can have a profound effect on a person's personality, and without advice or guidance this can be very difficult to understand.

... because you sometimes have unpleasant thoughts and feelings?

At times, you may feel that you don't even like the person you are caring for very much, let alone love them. You may feel embarrassed or disgusted by the behaviors of the person with dementia. You may sometimes want to walk away from your responsibilities, or even wish that the person were dead. You may worry that you are only caring for the person out of a sense of duty now that they seem so helpless and vulnerable.

These feelings are common and quite normal, but they can be very difficult to accept and many carers feel ashamed or guilty. You can't help or control how you feel about the person - but you can control how you respond to those feelings. Try not to judge yourself. Admitting to the feelings and talking them through with someone who

you feel will understand is often a first step towards ridding yourself of your guilt. Remember that you are helping the person enormously through just being there and carrying out your caring role.

... because you sometimes get angry or irritated?

If you feel angry and frustrated, you might occasionally have angry outbursts against the person you are caring for. Many carers find it hard to forgive themselves in this situation.

Try to remember that caring can be very stressful, and anger or frustration are natural in this situation. Look for ways of expressing your irritation away from the person, by finding the space or time to have a good shout, punching a cushion, or through some other outlet. If you can identify the particular situations or times of day when you are more likely to become irritated by the person, you may be able to develop techniques to diffuse the tension. If you feel you're about to react, try leaving the room and counting to ten.

... because you sometimes want time for yourself?

You may feel guilty about having time to yourself. If you still enjoy things that you used to share with the person you are caring for, you may feel that you are being disloyal.

Everyone needs to recharge their batteries now and again, and it's very important for carers to enjoy some time away from their caring role. Many carers find that giving themselves some time apart, and doing things that make them feel happy and positive, makes them more able to fulfil their role. This can improve their relationship with the person they are caring for.

... because of feelings from the past?

The history of your relationship with the person you care for may have a big impact on how you respond to them in your current situation. If the person was critical of you or made you feel inadequate in the past, you may feel even more anxious about not 'getting things right' now.

Many carers feel guilty that there are so many unresolved aspects of their relationship with the person they are caring for, and have deep regrets that it now feels too late to sort them out. If you are experiencing these feelings, allow them to surface rather than bottling them up, and explore ways to relieve the tension - for example, by talking them through with someone. Try to become aware of how these feelings make you respond. For example, do you push yourself too hard in an attempt to compensate in some way for the past?

... because you feel you shouldn't be 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 can be exhausting. Accepting respite care, such as help in the home, day care services, or residential care services, will free up some valuable time. This will give you more energy and may enable you to go on caring for longer. Even if the person with dementia is initially upset about others becoming involved, they may well come to terms with the idea. The first experience of separation often makes carers feel guilty and unable to relax, but in time you will probably both get used to the separation and see the benefits.

... because you feel you can't balance all your commitments?

For many carers, looking after a person with dementia is just one responsibility alongside many others, such as looking after their own family or having a job. It's easy to feel guilty if you are not giving total support to the person with dementia - but it's just as easy to feel guilty if you are not giving proper attention to your family or job. If family members, work colleagues or the person with dementia resent your other commitments, this can easily

add to your sense of guilt.

Don't feel you have to meet every demand made of you, but discuss your commitments with your family and colleagues. Give them the space to voice how they are feeling, and work together to set priorities, agree on areas of flexibility, and discuss what other forms of support might be appropriate.

... because you sometimes feel trapped?

It is easy to feel trapped if you are a carer, but there are certain situations that can be particularly difficult. Perhaps you want to continue with a full-time career rather than devote yourself to caring, but feel that this is selfish. Perhaps your partner developed dementia just as you were about to end the relationship.

It's important to talk this sort of dilemma through with a person outside the situation, such as a friend, community psychiatric nurse or counsellor. They should be able to help you to reach a decision that feels right for you, and to offer you ongoing support whatever decision you make.

... because you've decided that the person needs to move into residential care?

Carers often feel that moving the person into a home is the 'ultimate betrayal'. You may feel that you have let the person down, or that you should have coped for longer. You may have previously promised the person that you would always look after them at home, and now feel forced to break that promise.

Talk this through with someone who understands, and who can help you come to terms with your decision. Remember that any promises were probably made in a completely different situation, when you had no idea of all the strains and stresses that lay ahead. It may help to talk to other carers at a support group, but don't let others who are still caring at home add to your sense of guilt. Everyone's situation is different.

The move to a care home doesn't need to mean that you give up your caring role completely, unless this is what you want - it's just a different way of caring. Your involvement can still be very important. Some carers feel that residential care helps them to have a better relationship with the person, as their time together can be more special, less stressful, and more like it used to be before the constant worry about practical care.

Keeping on top of difficult feelings

Caring for a person with dementia can feel like a series of small losses. Each time a loss occurs, you have to make another adjustment, and carry on. To survive the caring process, you need to look after yourself and not judge yourself too harshly.

- **Tackle your guilt** If you are feeling guilty try to work out why. You will then be able to make clearer decisions about what is right for you and the person with dementia.
- **Talk things through** Suppressing pent-up emotions can be damaging; one of the most important steps you can take is to talk about your feelings - whether to an understanding professional, a good friend, a counsellor or anonymously, to someone at a helpline (see right).
- **Take a break** You will be better able to face the challenge of caring if you take enough breaks away from the person and find time for yourself. Try to find time to reflect and relax, to pursue interests and hobbies, and to socialise with friends and family.
- **Separate the past from the present** Try to find some way to separate in your mind your past relationship with the person from the current situation. Some carers say they feel as if they are relating to a different person, and that this helps them not to dwell too much on the past.