

Dealing with guilt

People who care for someone with dementia often talk about feeling guilty, even if others are reassuring them that they are doing the best they can. This factsheet looks at some of the issues that can cause these feelings. It explains why it is important to deal with them, and suggests some ways to go about doing 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 frustration and anger, are healthy responses to challenging circumstances. They can be useful, helping people to move forward. But other emotions, such as guilt, can be more difficult to deal with, and leave people feeling powerless or ‘stuck’.

While each person’s experience is different, guilt can be a very tiring emotion, consuming energy that you need for other tasks. If you have identified that you have feelings of guilt, you have already taken the first step towards addressing these feelings. The next steps are to:

- work out where these feelings come from
- realise that you are not alone in feeling this way
- find ways to develop a more positive attitude and to be more forgiving of yourself.

Circumstances that often lead to guilty feelings in carers

Other carers seem to manage better than you do

Meeting up with other carers at support groups or reading about other people's experiences 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 is no such thing as the 'perfect carer', and it's important not to be too hard on yourself. Are you being realistic about what you can achieve? If not, can you reduce any of the expectations you have of yourself, or get any more help? This help does not need to be from specific services such as those provided by the local authority. Sometimes just letting family and friends know how you feel may give them the opportunity to help out.

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 were not to know that they had dementia and you could not have foreseen what the future held. Dementia can have a profound effect on a person's behaviour and without advice or guidance this can be very difficult to understand.

It may help to keep in mind that although you can't change what happened in the past, you can still affect how the person you care for feels today.

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, and you may feel embarrassed or disgusted by their behaviour. 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 may feel ashamed or guilty.

You can't help or control how you feel about the person – but you can try to 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 dealing with these feelings. Remember that you are helping the person enormously through just being there and carrying out your caring role.

You sometimes get angry or irritated

If you feel angry and frustrated, you might occasionally have angry outbursts towards 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. People with dementia often pick up the feelings of the people around them and so they may react to your feelings even if you think you are keeping them hidden. Relaxation techniques, such as deep breathing, can help to relieve stress. Taking some time for yourself to do something that you enjoy – such as reading or exercise – can also help to improve these feelings. In particular, exercise can make you feel happier and less stressed, and can help to relieve your anger and frustration.

If you can identify the particular situations or times of day when you are more likely to become irritated (for example, at the end of a long

day), you may be able to develop strategies to reduce the tension or get extra support at these times. If you feel you're about to react, try to breathe deeply. It may help to leave the room and count to ten. This helps you to step back from the situation and gives you time to decide on the best way to respond.

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.

If the person you are caring for can't be left alone, ask friends or family whether they could pop in for a short time, or whether they could come and stay with the person for a few days. There should also be home care, day care or residential care services available in your area (contact your local social services department for details).

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 some 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 a friend or professional.

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? Understanding how these feelings from the past affect you could help you to view or respond to the situation differently, which may help you to feel better.

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. You may be able to free up some valuable time by accepting respite care, such as help in the home, day care services, or residential care services. This will give you more energy and may enable you to go on caring for longer.

Some carers may worry that the person with dementia will be distressed if they are not there all the time. 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 will be able to see the benefits this can bring.

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 useful. If appropriate, give them the opportunity to become involved in the person's care too.

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. This could be a friend, counsellor or other adviser, or you could use an online forum such as Alzheimer's Society's Talking Point. 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.

You've decided that the person needs to move into residential care

Carers often feel that moving the person into a home is a 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 what might happen in the future. 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 practicalities. Moving into residential care is, however, a time of transition – it may take the person and their carer some time to settle down and get used to the change.

The person's death

When someone with dementia dies, many carers say that they initially feel some sense of relief that the person is dead and any suffering is over. Then they feel ashamed or shocked that they have had these feelings.

Relief is a normal reaction. Many carers go through much of their grieving process throughout the illness, as they notice each small deterioration in the person as the dementia progresses. Talk to people about your feelings and remember that bereavement can cause a wide range of emotions, and there is no one 'right' way to feel when someone you have been caring for has died. For more information see factsheet 507, Grief, loss and bereavement.

Tips: 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.

- **Acknowledge your feelings** – It is important to acknowledge and accept any feelings of guilt that you have. Having negative feelings does not make you a bad person. Acknowledging and accepting your feelings will help you to move on.

- **Tackle your guilt** – If you are feeling guilty, try to work out why. Are you setting yourself unrealistic goals? You will then be able to make clearer decisions about what is right both for you and for 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, anonymously to someone on a helpline or discussion forum such as Alzheimer’s Society’s Talking Point (see ‘Useful organisations’).
- **Take a break** – You will be able to face the challenge of caring better 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.
- **Think about the good things that happen during your day** – Sometimes it may be difficult to see the positive and worthwhile things that you are achieving in your caring role. It might be useful to write down things that go well, even if it is something as simple as the person smiling or laughing as you care for them. On a difficult day, these things can remind you that you really are doing a good job.

Useful organisations

British Association for Counselling and Psychotherapy (BACP)

BACP House
15 St John’s Business Park
Lutterworth
Leicestershire LE17 4HB
T 01455 883316
E bacp@bacp.co.uk
W www.bacp.co.uk

National body representing counsellors and psychotherapists. They can help you to find a suitable counsellor in your area.

Carers Trust

32–36 Loman Street
London SE1 0EH
T 0844 800 4361
E info@carers.org
W www.carers.org

Works to improve support, services and recognition for anyone living with the challenges of caring, unpaid, for a family member or friend who is ill, frail, disabled or has mental health or addiction problems.

Carers UK

20 Great Dover Street
London SE1 4LX
T 0808 808 7777 (free carers' line, Wednesday and Thursday 10am–12pm and 2pm–4pm)
E info@carersuk.org
W www.carersuk.org
www.carersuk.org/forums (online discussion forum)

Provides information and advice to carers about their rights and how to access support. See in particular its factsheet about carers' assessments.

Samaritans

T 08457 90 90 90 (24 hours, seven days a week)
E jo@samaritans.org
W www.samaritans.org

Samaritans provide confidential, non-judgemental, emotional support, 24 hours a day, for people who are experiencing feelings of distress or despair, including those that could lead to suicide. To find your nearest branch look in the phone book or look on the Samaritans website (above).

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This factsheet has also been reviewed by people affected by dementia. A list of sources is available on request.



Alzheimer's Society National Dementia Helpline

England, Wales and Northern Ireland:
0300 222 11 22

9am–8pm Monday–Wednesday
9am–5pm Thursday–Friday
10am–4pm Saturday–Sunday

alzheimers.org.uk

Alzheimer's Society is the UK's leading support and research charity for people with dementia, their families and carers.



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