

Talking Point chat room 10 November
The guilt monster - dealing with feelings of guilt
when caring for a person with dementia.

SerenaS	Welcome to the chat room tonight :) Our session is about dealing with feelings of guilt when caring for a person with dementia.
SerenaS	If you'd like to post a message, ask a question, share your experience or just say hello, just type in the white box at the top and click 'Ok'
SerenaS	Caring isn't easy - so many discussions on Talking Point describe how difficult dementia can be. This can be all the more difficult to deal with when carers and relatives feel guilty. Do you have an experience you'd like to share, or something that has helped you?
Quilty	Hello, I am loaded with guilt trying to care for my mother. Each day I try to be patient and each day I fail. It's the fact that it's like groundhog day. I try to count to 10 and leave the room. It's very difficult.
Quilty	I also feel guilty about any life I have away from her but I have a husband and children who need me and deserve my time. What do the more experience carers do? I'm 2 years in and feel like a newbie
jaymor	Good evening Serena and Quilty
Izzy	Hi Quilty. I found my mum very hard to cope with sometimes. I often lost my temper and then would feel massively guilty when she would say 'I don't know what I'd do without you'. I cared for her for 5 years and my husband's diagnosis was 13 years ago. I still feel like a newbie!
Izzy	By the way good evening Serena and everyone else!
jaymor	Hi Izzy
SerenaS	Hello Quilty, thank you for sharing your experience. I'm sorry to hear that you feel that way.
SerenaS	Hello jaymor and Izzy :)
sisttermillicent	Hi all, I sympathise Quilty, I also feel guilty for the horrible feelings I have about my mum sometimes. I started out almost exactly 5 yrs ago and thought I would do all I could for mum despite living a long way off so that I didn't regret or feel bad when she died that I hadn't done enough. I have just hated doing things for her sometimes but have never regretted it. Unfortunately I know that whatever I do I will feel bad for not having done more, you can't win sometimes .
jaymor	Quilty you should never feel guilty for any time you manage to get for yourself and your family. Caring is a difficult job and finding time for yourself is important as I am sure your Mum would agree with.
sisttermillicent	Quilty you're only human like the rest of us, what you say sounds like you're normal and better than most because you're caring for your mum.
SerenaS	Hello sisttermillicent - I think you've hit on an important point about the guilt that carers feel when they're actually doing all they can to care for their loved ones.
Quilty	It never feels like or seems enough. It's hard to leave her when she looks so lost
Quilty	I have a sister who does almost nothing. I don't know how she lives with herself. I could never walk away
sisttermillicent	I think a lot of us have siblings who don't contribute much, quilty, I could tell some stories about mine, but as you say, they have to live with themselves.
Quilty	The thing that keeps me going is this: what's the alternative? At the moment me caring is best. Until that changes, we endure. Also, my kids see that you care for your family - thick and thin. I don't say that as if I expect my kids to do the same. Just to care for others when they can.

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Dunkery	Hi All, I cared for my mum up to just over a year ago and now she is in a lovely care home. I often felt guilty when I lost patience or when I went out, even though I always organised a sitter for her. Mum frequently became upset because she wanted me there all the time. I still feel guilty now when I visit and she asks when she is coming home, even though I know she is much happier in many ways and the staff are meeting her needs much better than I could in the last few months of her being at home.
Dunkery	Someone who has also been a carer told me the guilt never completely goes away but in time it does become easier to live with and I think that is right. Also, we are all human and cannot be perfectionists!
rogibob	The guilt is awful even when go to the home nearly every day. I always think she shouldn't be there but home with me.
sistermillicent	I wonder if guilt is made worse by sadness and that feeling of loss, even though the person is still there.
Dunkery	It is hard rogibob. I go every 2-3 days. The one positive thing now is that my relationship has returned to that of mum and daughter. When mum was at home we lost that somewhat and I felt it was just a carer/ patient relationship because everything was a battle. I am so grateful to the staff at the care home for giving back that precious relationship with my mum.
jaymor	I might be out on my own here but I don't feel guilty that my husband is in care. I cared for him at home for 7 years and really should have probably admitted defeat a few months earlier and not waited for a team of professionals to tell me his needs were too complex for me to cope with. He has been in care for 2 years now and with the right care has been less tormented and more settled.
Quilty	Jaymor I don't think you should feel guilty about your husband being in full time care. You do your best for those you love and that is what you have done. Again - the alternative of being home is not best for him now,
Dunkery	Jaymor, I think it is good that you don't feel guilty and that you can see your husband is more settled. I feel less guilty than I did, because the staff involve me so much in all decisions and keep me informed-we are "sharing the caring" in many ways.
sistermillicent	I feel relief, Jaymor, when mum goes into respite, which she does every six weeks, because I know they look after her so well, I am glad you said what you did as I wondered if I was hard.
rogibob	I also felt like that when mum was in respite but now it just feels wrong. I looked after her for 2 years at home and it was hard I feel lonely now.
jaymor	The staff at my husband's care home care about me and my wellbeing as much as they do my husband's. To me this makes life so much better and I have quality time with my husband, something that had long gone whilst caring at home.
SerenaS	Hello Dunkery and rogibob :) Some of the discussions about guilt on TP mention that the feeling can be really powerful but it isn't logical.
Quilty	I can understand that sistermillicent. I don't think I will ever be without worry until mum is in good full time care
Dunkery	Thank you for that reminder Serena
Dunkery	I thoroughly agree Jaymor. I also have so much support from other relatives of residents at the home, who really understand what it is like.

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SerenaS	Sometimes people on Talking Point talk about 'the guilt monster' - an unhelpful form of guilt that can plague people. Lots of discussions talk about 'putting the guilt monster back in its box'. How can we deal with guilt?
sistermillicent	Serena, this probably isn't the answer you want but I have found the mindfulness techniques very useful for dealing with guilt and all sorts of other things, it helps you to feel ok in the present moment and learn how to keep that up.
jaymor	We should do just that Serena, put it in a box and nail the lid down. Guilt is for those who do not care, not for those who do care and care so much that they feel guilt when they cannot deal with something that is probably not something that can be dealt with.
SerenaS	Thanks jaymor - that's a really important point. A person with dementia may progress to the point that they are best in a specialist home where professional care can be given around the clock. One person simply cannot offer 24/7 care.
Dunkery	I also find the relatives' support group, which meets monthly, a real help.
SerenaS	Thanks sistermillicent I think that's helpful. Taking a step back and thinking about things can be very helpful.
Dunkery	I too use mindfulness techniques and it helps with anxiety too.
rogibob	But you cannot help it, when you walk out of the home and they say I'll come home with you now.
SerenaS	This may be helpful too - guilt can come from feeling that you shouldn't be cross, feel frustrated, take a holiday etc. Of course, the truth is that we are all human and we all need to express our feelings and recharge our batteries. We are human.
Dunkery	That is true Serena and a better way of putting it than the comment several people said to me when mum went into the home that "you are entitled to a life of your own" It may be true but somehow seems selfish.
SerenaS	Have you spoken to the care home staff, rogibob? Can they help at all? It may be that a distraction is needed so she doesn't notice you leaving.
jaymor	Do you think we can sometimes mix up a feeling of great sadness with a feeling of guilt? I'm sad my husband can no longer recognise his family, has no idea of the arrival of his latest grandchild and can never sit down with his family for Christmas lunch as he did for 46 years. I'm very sad when I think about this. I can't say it is guilt because I can do nothing about it.
rogibob	Jaymor, you are so right it's not guilt really its great sadness
SerenaS	Thanks jaymor - so much of the frustration and anger could be about how unfair and horrid dementia is.
Dunkery	I peek through window from car park and even though mum looks sad when I leave the lounge, she looks quite content a minute later. It is a bit like leaving children at school when they are upset!
Dunkery	Jaymor-that makes a lot of sense
Dunkery	I have found this discussion really helpful-thank you all!
SerenaS	We've just a few minutes left of today's chat room session on dealing with guilt. I'll be including some helpful resources in the transcript of this session, and putting it on Talking Point later this week.
rogibob	I would like to thank you all x

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SerenaS	One thing I'd like to mention before we go - please do visit Talking Point as often as you need to. There will often be someone else who knows how you feel and may be able to help.
jaymor	Dunkers if our discussion tonight has helped just one person nail that lid down on the box, we have achieved something. Good night everyone and thanks for the chat.
Izzy	Good night,
SerenaS	Many thanks to everyone who took part in tonight's chat room session. I do hope that it was helpful.

Thanks for reading the transcript from our chat room session on 10 November.

Some helpful resources on this topic are listed below:

Alzheimer's Society factsheet on dealing with guilt:

http://www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=105

Adjusting as a parent's dementia progresses – a helpful article from our magazine *living with dementia*

http://www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=2255&pageNumber=2

Coping with caring – information on Alzheimer's Society website with information and support for carers

<http://www.alzheimers.org.uk/site/scripts/documents.php?categoryID=200358>

Alzheimer's Society factsheet on grief, loss and bereavement:

http://www.alzheimers.org.uk/site/scripts/download_info.php?fileID=1796

Alzheimer's Society factsheet on talking therapies (including counselling, psychotherapy and CBT)

http://www.alzheimers.org.uk/site/scripts/download_info.php?fileID=1781

Alzheimer's Society National Dementia Helpline

If you would like to talk about your feelings with someone trained to help, Alzheimer's Society National Dementia Helpline **0300 222 1122** can provide emotional support, as well as guidance and signposting to other appropriate organisations.

The Helpline is usually open from 9am to 5pm Monday to Friday and Saturday and Sunday 10am - 4pm. You can email the helpline team at helpline@alzheimers.org.uk.

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If you have questions about our chat room, please contact us by emailing talkingpoint@alzheimers.org.uk

You can view the chat room here: <http://forum.alzheimers.org.uk/chatroom.php>