

Talking Point chat room 22 September 2014
Dementia Support Chat: Coping with guilt

KatherineW	Hi and welcome to the TP chat room. :)
KatherineW	Today's session is on the topic of coping with guilt. If you'd like to share your feelings and experiences in relation to this topic with other members, please do pop in to the session. Posting a message in the chat room is easy: just type into the white box at the top of the screen, and click OK.
KatherineW	Guilt is an emotion that comes up all too regularly on the forum: we've seen posts from members in a range of different situations expressing feelings of guilt. For example, guilt about being a long-distance carer, guilt about making difficult decisions, such as a move to a care home, or guilt about having conflicting feelings towards a loved one with dementia. These are just a few examples, and of course there are lots more...
jeany123	There are 2 kinds of guilt the justified and the unjustified I think most people on here are doing their best so it is definitely unjustified
Lindy50	Well said Jeany :)
KatherineW	Hi jeany, that's a very good point. As you say, the type of guilt that tends to be posted about on TP is from those who are doing their very best. Hi Lindy. :)
jeany123	That doesn't stop us feeling it though
KatherineW	I know jeany. Feelings aren't always logical and rational, are they?
KatherineW	Lindy and Jeany (and others who may want to join in :)) - are there specific sorts of situations or things that you have felt guilty about, in relation to being a carer?
jeany123	The things I feel guilty about are things that are usually out of my hands I wish I could just accept this.
Dazmum	I don't think I will ever stop feeling guilty about my mum needing to be in her nursing home, even though I know in my heart that I couldn't look after her myself.
Darren 48	Hi everyone me and my wife have been looking after my 83 yr old mum without anytime out for ourselves .On Tuesday mum is going into respite care for two weeks so we can have a couple of days break to recharge our batteries but we feel guilty for doing so and with one day to go the guilt is getting worse but we know without a break we will crack up x
berkeley	I used to feel guilty now I just feel cheated
KatherineW	Hi Dazmum. The move to a care home is such a painful decision for so many on TP, and sadly guilt seems to almost always be a part of that decision.
KatherineW	Welcome Darren and berkeley. :)
jeany123	The fact that Allen has to go to a day centre 3 times a week to save my sanity and he cannot understand why because he thinks there is nothing wrong with him
KatherineW	It sounds like for a few of you, taking breaks from caring, no matter how short, is a huge source of guilt. :(

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Dazmum	It's really easy to tell others that they shouldn't feel guilty, that they have done their best and owe it to themselves to have a break, be it respite or other more permanent care, but so hard to accept in respect of yourself. I wonder why that is?
Oxy	I think we have a complete range of emotions but do not always classify them as guilt-don't know.
berkeley	Tried day centre but they couldn't cope so haven't even got a few hours respite
KatherineW	You're so right Dazmum. I wonder is it partly about control: we wish we could fix things for the people we love, and when we can't, perhaps it's inevitable we might feel we have failed them - even though there's only so much we can do. Hello Oxy. :)
KatherineW	Berkeley, I'm really sorry you haven't got access to respite care. Are you saying the day centre couldn't cope with the person you are caring for?
Oxy	A lot is written about respite but getting a respite place is not easy. It should be law that each home regardless of whether private or not has to reserve rooms for that purpose. Also getting care is a nightmare and there comes a point where one is too low to bother then.
berkeley	Yep my OH will not settle. do you not think sometimes that your 'loved one' has failed you. know that sounds horrid but that's the place I am in now
berkeley	Quite agree Oxy sometimes it is all too much
KatherineW	That's really tough berkeley. I'm assuming different tactics have already been tried to see if they help your OH settle? Access to care services can be patchy, and it's so unfortunate that those who need it most, may not have the energy to fight for good care and support.
Grannie G	Hello everyone. :) I wish TPer's were able to apply the advice and support they give to others to themselves.
Darren 48	Oxy you are right about trying to get respite care as we still don't know if mum has a bed or not we won't know till morning or where she is going to.
KatherineW	Hi Sylvia. :)
Grannie G	My husband wouldn't accept day care so I was given Direct Payments so I could get someone in on my terms. They came on the pretext of coming to help me and they were so good I was able to have the free time I needed.
KatherineW	That's good to hear Sylvia - it sounds like you found a good work-around.
Dazmum	It took my mum several weeks to settle, so it is not surprising that people don't over a day I suppose, maybe it feels strange every time they go. I suppose staff should be able to deal with it, as it must happen a lot I would think.
Oxy	I may have alluded to this before but I really feel that much a made of dementia friends. However when we are in the thick of it would be nice to have a café/room available for carers and carees to meet up casually. This would also afford the chance to find out about CH reputations for respite etc as well as giving carer social contact. And maybe carer know how. It is all a postcode lottery-hard actually.

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nellbelles	Sylvia you are quite correct, things would be better if I could take my own advice.
KatherineW	I would think staff should be used to settling people with dementia into respite too, Dazmum. It seems obvious that a person with dementia might struggle to settle, for all sorts of reasons.
jeany123	Yes Sylvia I am good at giving advice and know that it is right but it is difficult to take my own advice, Allen always has a way of tugging my heartstrings then the guilt comes
KatherineW	I'm wondering if there are things that help people to cope, when the guilt comes?
Oxy	Dazmum it must be nice to go out. Mine isn't dressed yet today! Gets so tired. Unfortunately vices e.g. food and cigs help to make upset better
Darren 48	My mum has lived with us for nearly a year now and she still thinks she lives in her bungalow on her own. So by putting her in respite care I'm not sure what that will do to her confusion.
Oxy	I was once told it takes 4-6 weeks to settle and we are unlikely to take that long as carers allowance doesn't allow it!
Dazmum	My mum does too Jeany, without even trying to. I can't bear it if she is upset, and I try to take her places and do things with her to distract her. At least she does forget that she was upset, but I don't. Then I go away sad, and bang, down comes the guilt monster.
KatherineW	It sounds hard Darren, that sense of not knowing whether the respite might cause your mum more confusion. Oxy - 4-6 weeks to settle sounds a bit random to me: surely everyone is different.
Oxy	Katherine - you are so right about depending on person. I do think approach of staff can help though to a degree.
Oxy	Another source of guilt is feeling cross about something said that is not really them i.e. under influence of dementia
Grannie G	Hi Oxy. It's so easy to be wise after the event. I lost it with my husband many times. I didn't feel guilty at the time, it was only afterwards when I calmed down and he calmed down I felt I could have handled it better.
Grannie G	When we are tired out and stressed out we don't always do the right thing.
berkeley	Why is it wrong to feel cross? Aren't we all cross with this awful disease?
KatherineW	So true re. hindsight being a wonderful thing, Sylvia.
Oxy	I do sometimes let frustration on myself - don't let rip at source. Also feel that I'm always giving in in a way I wouldn't with a child - and wonder if that creates more demanding behaviours.
KatherineW	I don't think there's anything wrong with feeling cross berkeley. It's an entirely understandable feeling and it's important people have the opportunity to express it - e.g. here on TP. I suppose though the guilt might come if crossness is expressed at a

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	person with dementia, but it's almost inevitable that that is going to happen, especially for those who are caring 24-7, and often without breaks or the practical support they need.
Izzy	Sorry I'm late to the chatroom. I feel huge guilt when I have lost my temper with Bill. I know he can't help it - whatever 'It' is but there are times that frustration/tiredness takes over. I feel awful afterwards. The other thing I feel guilt about is when I occasionally go away without him. I am lucky enough to be able to have respite at home. He is always fine but he always knows I'm not there. He was up through the night last night wandering. I think looking for me.
Oxy	Does anyone else find they give in a lot and then feel selfish a bit for thinking if only someone would give me a thought once. This is not all the time but does happen.
Oxy	My feeling I mean. I do give in to every wish.
Grannie G	I think when you care 24/7 Oxy, you put your life on hold and it's only natural to get a bit fed up of it at times. It doesn't stop you feeling selfish but it's still only natural.
Oxy	Thank you GrannieG
Grannie G	What used to help me was thinking better I have to care for Dhiren than he have to care for me.
Oxy	That is true GrannieG
Izzy	I think that often Sylvia. I know Bill was perfectly capable but I don't think he would have coped as a carer.
KatherineW	Hi Izzy
Oxy	How much time off is considered reasonable?
Oxy	Assuming there was a replacement of course!!
KatherineW	Others might feel differently Oxy, but I would think it's less about what's reasonable, and more about what you as an individual need, in order to be able to cope?
Grannie G	As much time as you need to recharge Oxy.
Izzy	Oxy have you had a Community Assessment - to determine needs?
Oxy	Yes
Lindy50	Great! Sorry I had to rush off earlierOne silly thing that I feel so guilty about, that I haven't managed to do it.....is setting up a funeral plan for mum. I feel sick just thinking about it, and I don't think she agree if she knew, if you see what I mean. And yet, her financial position is such that I know I should do it.....
Izzy	I'm sorry if you've already told us this but did anything come of it regarding time you might get for care/cover?
KatherineW	I don't think that's a silly thing to feel guilty about Lindy. Having to make big decisions, when you're not sure whether your mum may have acted differently if

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	things were different, sounds really hard.
Lindy50	Yep, and I have an 'invisible' brother - he sees mum maybe three times a year! - I made the mistake of consulting him, and he thought it was a horrible idea :(
Lindy50	Brother has No Idea...he thought mum " would have it covered". What planet is he on????
Oxy	Lindy - are these not long term plans? I could be wrong. Please don't feel guilty. I also have missed the boat with something where she asked me to help her and I couldn't face it. We are humans and sometimes our hearts don't help us.
KatherineW	Well - I guess you can't please everyone all of the time Lindy, but it really sounds to me as though you are trying to put your mum's needs first, and do what's right by her.
jeany123	I am lucky that all my family back me no matter what
Lindy50	Oxy, they cost around £3,000 + and you can either pay a lump sum upfront, or monthly instalments. The thing is, it's not considered deprivation of assets so my head knows it's right....but our hearts do feel differently don't they? sorry you feel you missed the boat....:(
KatherineW	Sorry to cut things short but I'm going to have to close today's session. Thanks to everyone who has joined in, as well as those who've read along. I'll get the transcript posted on the main forum asap, and will add some resources about coping with guilt. Bye all. :)
Izzy	Thanks Katherine. Bye all.
Lindy50	Bye all...xx
Grannie G	Thanks Everyone. Bye!

Thanks for reading the transcript from our chat room session on 22 September. Some helpful resources on this topic are listed on the following pages.

Alzheimer's Society factsheet, Dealing with guilt:

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

Alzheimer's Society information pages on Coping with caring:

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

Alzheimer's Society factsheet, Carers: looking after yourself:

http://www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=119

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Alzheimer's Society factsheet, Talking therapies (including counselling, psychotherapy and CBT):

http://www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=92

Carers UK information on coping with guilt and resentment:

<http://www.carersuk.org/help-and-advice/health/looking-after-your-health/guilt-and-resentment>

Mayo Clinic's Tips for caregivers to help lessen the guilt:

<http://www.mayoclinic.org/diseases-conditions/alzheimers-disease/expert-blog/tips-for-caregiver-guilt/bgp-20055859>

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.

The Helpline also run a Live Online Advice service, which is available 9am – 12pm Monday to Friday, and 3pm – 4pm Saturday and Sunday. Click on the link below to begin an online conversation with a Helpline Adviser:

http://www.alzheimers.org.uk/site/scripts/home_info.php?homepageID=428

You can email the helpline team at helpline@alzheimers.org.uk.

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>