

Its not easy coping with dementia!

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Dementia has many forms.... This was written in 2010 when my husband was suffering with dementia.

So, dementia has crept stealthily into your life too? It may be someone very close to you or a friend who you would like to support. For whatever reason this disease comes to your attention, believe me it will be there a long time, because this is a long slow illness and for the carer it's better to know as much as you can, as soon as you can.

The effects of dementia are felt most keenly by relatives, especially when, as is often the case, a relative becomes the carer with no previous experience, no training and little idea of what the future may bring.

In fact, for most people finding themselves in this situation, the situation can be daunting and as the person's illness progresses the caring becomes more difficult, tiring and trying.

My introduction and involvement with dementia came first with my mother, now long departed, and currently my husband; Alzheimer's in both cases. My sister took the brunt of the caring with our mother, but until he was taken into care, the day to day monitoring of my husband's condition was down to me.

We are a second time around couple with six grown up children between us. Peter's family have little time or interest in us and my family, and although they love him dearly, they live too far away and have young families to bring up so are unable to provide any support. The reason Peter is in care, as he has been now for three years, is because of the toll it took on me during the previous five years of his steady decline. For the final three years at home, he was not safe to be left alone, so even though I managed to get some respite help, the 24/7 caring became just too much for me.

I have to live with the guilt, but I know that he is in a better place, especially now.

During the last few years together, Peter also suffered from prostate problems which, for a while, meant he had to have a catheter in place. He would look at the contraption and ask what it was; I would tell him and five minutes later he would ask again. If my attention dropped he would try to take it out, painful and distressing for both of us. Also, he would regularly wet the bed and the constant round of washing and drying became a daily chore.

He is now 86 years old and is become increasingly frail, doubly incontinent, had a broken hip early in the year and has not known who I am for some time. I hope this will be his last winter as his quality of life is not what he would have wanted, but there is little anyone can do about that and I think we take better care of our aged or sick pets. People don't die of dementia, they die with it.

If this is happening to you or a loved here are some of the practicalities:

1. Get your GP to refer your person to a specialist as early as possible. I am not known for my love of pharmaceutical chemicals but in this case, it may just help to subdue symptoms and extend the good times for a little longer.
2. Ask for help. This is most important if you find yourself pretty much a lone carer. You need time for you, to recharge and rest.

3. Find your local branch of The Alzheimer's Society who run activities for those with dementia and also have a befriending scheme. It's good to meet another carer with experience of what is happening to you, who will come and sit with you every so often for a chat and a coffee. You can unburden your worries and anxieties, knowing that you are talking to someone who understands what you are going through.
4. Get a social worker involved; they can help to find Day Care places and arrange respite care in a care home for a week every so often, just so you, the carer can get a break.
5. Please note that it is useless to contradict or argue with a sufferer; this is a waste of your energy and may add to their confusion. Respect that the way they are thinking is right for them. For instance, Peter would often tell me he was talking to Dennis his brother, who had died years before. I accepted that this conversation was real to him and I would just nod in agreement. We have no way of knowing what is happening in the sufferer's mind, so always give them the space to think what they want to think.
6. If the sufferer's behaviour become violent, there are gentle sedatives which can be prescribed and in some cases 'distraction' will work just as well.

At the start, you the carer may think that you won't need to take a break or go on holiday without your loved one, but this is unrealistic. Believe me, I love my husband unconditionally, but the constant caring wore me down and I got so tired I was at my wits end. Caring was such a tie and I was unable to go to the shops, get my hair done or see friends. I have always worked and even working from home became impossible. I never wanted to see him go into a home, but it was inevitable as my sanity too was tested.

Going back to Day Care.... Peter was not very keen on it to start with. I think the activities made him feel like he was at school! But as time went on he would proudly give me a pot for the garden that he had painted, or a picture he had coloured in, though by the time he got home mostly he had forgotten that he had done it and thought it was just a present for me. All in all, Day Care can be a great release for both carer and sufferer, because it's a change of pace for the sufferer and a chance for the carer to take care of themselves.

Learn as much as you can from the internet and your specialist consultant. You may be referred to a Mental Health Team, in which case you will have a case worker to talk to. Ask questions; you the carer need as much information as you can get. Ask about the side effects of the medication, keep a diary of symptoms, mood swings and incidents. This will be powerful evidence if you need to move onto expensive new drugs in the future.

Once in the early days and while I was out of the house, Peter cleared out the fridge to put his shoes in. Reason? He wanted a shoe rack and couldn't find one. Quite logical to him and...well I can't tell you what it did to me!

In the early days, he would walk our dog every morning, but as the disease progressed he would get lost. I would get a call from the local Police to let me know they had picked him up, miles from home. The first time he went missing the Police only knew how to get in touch with me from this house key fob which had a tracer telephone number, but of course he had no recollection of his address or telephone number. I got the call after I had been driving round the area for an hour or so and you can imagine my relief when the person on the phone said..."We have a gentleman here and

a little dog. Are you missing them at all?" The local station opened a file for him and several times I got the call to go and collect him and our dog. Of course, that could only go on for so long and eventually I would have to go with him everywhere.

Around that time, he turned on the gas fire but had forgotten how to light it, so I arrived home to find the house smelling of gas.... good job I was only out for half an hour. It was after that incident I realised that I would be unable to leave him alone again.

Travelling got difficult as well. We would stop at a motorway pit-stop for him to use the Gent's loo but of course he could not understand what to do and then how to get out. Men would look at me oddly as I peered into the loos, calling for him. Of course by then he even needed help to wee..... well, no more on that one!

I would make one major observation about dementia that may sound odd... please keep your sense of humour. Laugh when you can, see the funny side of the strange things that happen, look for the good things every day and never lose your own personality. When you become so immersed in the day to day chores and uncertainty of living with dementia, your own needs can get lost in being 'the carer'.

I am able to talk about the times before Peter's illness got a hold, to remember those shared moments of a long life together. The more recent happenings are still a little raw as I miss him just as much as if had died. In fact, this long bereavement that is still going on is not easy to think about. I go to see Peter about once a week and try to live my own life between visits. He is well cared for, clean and fed and is not aware that I am there or who I am. When I do go, I find something to do for him; I trim his nails and cut his hair when needed, as these are things he loved me to do when he was still with me. The last time I did this, he quite happily slept through the whole procedure! Well that made me smile anyway.

Peter is in now in a Care Home which is a specialised dementia unit, so whatever he does that's strange is not noticed by anyone and the staff are watchful, so no one gets angry or upset. The age range in the home is extraordinary and some residents look so young that at first, I thought they were staff!

Dementia can strike earlier in life that I realised; it seems such a shame when the body is fine and only the brain is sick. It's the carers who suffer too, as we watch our loved ones slowly decline and are left without a partner or parent; in my case I am still married but have had to adjust to living alone.

I have ways to deal with my grief and my sister is still there for me when I get sad. But mostly it is in learning to deal with feelings of guilt while waiting for the final goodbye that is my greatest challenge.

Thankfully, I practise EFT (Emotional Freedom Techniques) so I can tap to relieve the stress, simply accept the situation and forgive myself which takes away the guilt. I know that I have done the very best I can and continue to watch over my beloved until he dies.

Postscript; Peter died December 2010 ages 86