

My Husband's Dementia is Unbearable

I AM 73 and have been married for 54 years — with one daughter, who lives and works abroad. My husband is 81 and suffering from vascular dementia. He has expressive dysphasia, incontinence and is almost completely immobile, necessitating two carers calling four times a day. They are excellent and give me lots of support and in general I am better off than many other people. But after 15 years of this degenerative disease I am coping very badly. I dread waking in the morning and I am starting to feel very resentful. This is not how I imagined my golden years. My daughter is a great support and has offered to return home to help with her father's care (she has already arranged a shorter working year in order to come home more frequently), but I cannot even think of it. The obvious solution of course is a residential home, but I gave him my word this would never happen. I try to visit my daughter as often as I can. But the effort and forward planning needed make things very difficult. A counsellor was excellent, but funds ran out, then I was limited to only a few sessions on the NHS. I have contacted associations such as Age UK, but they seem to miss the point — arranging lovely outings and lunches for carers, but forgetting the need for respite care for loved ones while we arrange our own entertainment! On the scale of things, we've had a good life and perhaps it's wrong of me to complain, but at the moment I just feel like walking away from it all. Can you help?

Tina

Bel Moony's Reply

Just imagine, when young, that we could gaze into a crystal ball and witness our future unfold. How many of us would want, in terror, to give up right away? And yet, as the days, months and years pass, and we find ourselves exposed to stress and pain, how often do we realise that far from being defeated by sad and bad things we never predicted, we have proved our humanity by enduring them? The finish may rarely be worthy of the start, and yet sometimes it glows like a lone candle in a dark world. I don't say this to offer easy 'good comes out of suffering' folk-wisdom, because that would be an insult to what you endure. It would also deny the courage - and desperation, rage and sorrow - of all those forced to care for loved ones when that duty has become a burden (yes) they never envisaged. And yet what I say is still true. Every day individuals like you do what you have to do because there seems no choice - and yet that selfless shouldering of the burden of caring adds to the collective goodness of the world. Even if you do not know it. Can I just say one thing? I think it is wrong for anybody to give a promise - or anybody else to exact a promise - about the future when none of us have any idea what circumstances will be like. There can come a point in the life of a person with a serious illness when it is impossible for a partner to continue caring at home, even with help. If the time comes when it is imperative for your husband to be taken care of somewhere else, where you can easily visit, then I do not believe you should have any sense of guilt about that. People and circumstances change and sometimes we have to change with them. You clearly have an excellent relationship with your daughter and I am impressed and touched that she has offered to come home to help you. Tell me, why would that be so wrong? Surely she would not have offered if she did not think it practical? Obviously, it would have to be possible for her to find part-time work, but if that could happen then in the long term she might feel glad of the chance to be such a help to her mother. You are her parents; she is your only child. In my book, that has massive meaning and importance. It sounds to me as if you should move heaven and earth to arrange some respite care as soon as possible, and go to stay with your daughter to discuss

the future. But never say 'never.' Never say you would never ask her to come home. Never say you would never consider it better for your husband to be in a residential care with professional, round-the-clock help. Having plans and projects gives us a glimmer of hope. I'm sure you know about the Carers Trust (carers.org) and I think it would be a great idea for you to follow up any leads, anywhere, join forums to talk to other carers, and so on.

You are brave, resourceful and grateful for the blessings you have had. As you take care of your husband, day by day, you have every right to plan and dream to help make your life better. But please don't keep your daughter away. You need her

