

# A carer's lament

The consultant to whom our GP had referred my wife said it was vascular dementia. This is said to affect a different part of the brain from Alzheimer's disease. Fifty years ago it would have been just senility. To the carer, in regard to the patient's behaviour, it's all the same thing, endlessly bewildering, aggravating, patience-exhausting. It helps to have a sense of humour. To a prospective carer who might be short in that department my advice is DON'T DO IT — but the chances are that you won't have a choice.

After a couple of years the family thought I was looking a bit battered and urged me to take some respite. I had heard about a BUPA care home nearby and went to look it over. I was very impressed and thought it would be an agreeable place for my wife to stay for an occasional visit and booked a room for her for 1 week. There was much discussion about how to get her there because we all knew it was going to be difficult. We eventually devised a plan whereby there would be no mention to her in advance and I was going to explain things to her after breakfast on the morning of departure. I would then take her there accompanied by one of the carers who has been helping with bathing and so on for over a year and is very experienced and makes her laugh.

It was a dreadful morning. When she had grasped that she would be staying there without me she refused to go and there was a terrible scene. In desperation I rang our son in London and he came down hotfoot. Fifty-five years old, and a man of the world, in his mother's eyes he can do no wrong. But when he had failed to persuade her into the car and she became violent threatening him with her stick he was reduced to tears — something I had never witnessed since he was a small boy. So it was all called off and I wrote to the doctors who had been very helpful.

*Following my disastrous misjudgement of my ability to lure my wife into the BUPA home it has been suggested that*

*another family conference should be held. I think that is a good idea but it might be difficult to arrange.*

If such a meeting is to be fruitful I think the first thing is that I, being so to speak at the front of the firing line, should set out my feelings as truthfully as I can. So here goes, but I must admit to being in a state of some mental and moral confusion about the whole business. Please remember that we have had no experience of our situation whereas no doubt our difficulties have been encountered by you many times before. I think the main motive for the BUPA home exercise was to give me a break. I have read a lot of stuff about the stress imposed upon carers and their need for regular breaks and my son and daughter have been pressing some such arrangement upon me. I am not sure whether they really thought I was in danger of cracking up or they were worrying about what to do if I were in some way deactivated. Anyway, I don't think I am in danger of cracking up.

But aged 83 I sometimes I get tired and I must say it would be nice to have a break if it could be arranged without causing their mother too much agitation. When I look around and see what other carers have to put up with I suppose I shouldn't complain. I have a garden in which there is always something to do and where I spend a little time in the afternoon; usually manage to have nine holes of golf once a week with old pals, and when one of the lady helpers is on board I slip away for an hour or two.

But I am always aware that things are going to get worse. There is undoubtedly a lung problem that causes her trouble and she is increasingly immobile and wobbly on her feet, but otherwise I don't think others are fundamental health problems. Her heart, sight, hearing, bowels are all more or less OK. So she might go on 10 years sitting in her chair doing nothing but requiring always more attention. Am I to spend those years as a slave to her needs and with less and less in the way of

companionship? I think I have a right to consider myself as also having some rights, haven't I? When this all started we thought that at all costs we must somehow arrange for her to stay in her own home. But recently I have been beginning to wonder.

I don't think that others who have not actually been in the role of a full-time carer can really understand what it involves. So perhaps I should try to explain the things that really hurt.

## TANTRUMS

When these happen I find them very distressing and I seem to spend my life trying to avert them and keep her calm. Our son saw it all when he was here including the violent bit and I think he was considerably shaken. It tends to happen when going to bed. I give her the lorezepam pill, to which she has been addicted for some years. She sometimes asks what they are supposed to do, and then half an hour after she has taken it she has forgotten and demands another, and when I tell her there isn't another she calls me a liar and gets abusive. So bedtime is tricky. Otherwise the tantrums tend to recur when she becomes frustrated or angry.

## DEPRESSION

She tends to have bouts every autumn and it has been particularly bad recently. She moans away about how useless she is and how bored she is and hopes it will soon all be over. Her antidepressant dose (venlafaxine) was recently doubled and I wait to observe the effect.

## DEPENDENCE

I find her total dependence on me very trying. She becomes very agitated if I am not within sight and she doesn't know what I am doing. This was the main difficulty in the BUPA care home saga when it dawned on her that she would be going there alone. She wouldn't understand that I might be in need of a break. She complains that we never go on

holiday — ‘All very well for you, you are on holiday all the time!’ — there is no answer to that one. A holiday in the ordinary sense is not possible, a hotel out of the question because of stairs, bathroom needs, nursing and so on, but one could not explain that to her. She has nothing to occupy her, just sits there and dozes and worries. I read the other day that people who don’t take regular exercise are more prone in old age to dementia. This probably applies to her. I try to take her for a bit of walk in the grounds every day. She would never go for a walk by herself, nor, now I come to think of it, do anything else by herself. She would have been best suited to the old traditional Chinese ways where three generations of the family dwelt in the same residence all in separate little hutches around the courtyard dominated by revered Grandma. She expects constant attendance to her needs.

‘Ronnie, Ronnie — can’t find my glasses, left my stick downstairs, left book upstairs, glass of water please, my drink’, and so on. I take refuge in my office but she resents this. Usually if I start doing some work there I get ‘Ronnie, Ronnie’. Sometimes I wake in the night hearing ‘Ronnie, Ronnie’. Wide awake now I wonder what’s happened, but no it was a dream.

She is obsessed about food and can’t get it into her head that she no longer needs to be responsible for the shopping and the meals she regularly says she wants to go shopping for, although she hasn’t done that for over a year. I try to deter her but she insists. Says she will go to the butcher and I will do the rest. I know she won’t do it but she insists. Nothing happens and she admits she can’t do it or starts to walk down the drive and turns back. Same story with cooking. She says she wants to cook supper. After countless questions ‘What shall we have?’ I get desperate and write down a menu. Later I look into the kitchen and find she has started to prepare something quite different. Then she forgets what she is trying to do, starts to

get angry and ‘Ronnie, Ronnie’, has to take over.

But she still seems to believe she does the lot and when she calmly tells that to people I struggle to keep my mouth shut. She complains about all the years she has had to do it all by herself and how she is bored with it, but when I suggest ‘Why not leave it all to me?’ she won’t consider such a ridiculous idea. It would be so much easier if only she would leave it all to me.

You can’t win!

### MEMORY

Anything up to about 20 years ago and her memory is acute, clearer than mine. But since then it is terribly confused. She spends hours gazing at her diary but never knows what day it is. You can’t rely on anything she says because 5 minutes later she will have forgotten. It seems that she can’t relate one thing to another. She asks if anyone is coming today. Beryl? (She has been coming twice a week for at least 6 months). Who is Beryl, what does she look like, what’s she come for? She likes Beryl and when she turns up they always get along fine. Like my food menu or shopping list she might look at it but it doesn’t seem to mean anything to her. I suppose she can’t think in the conventional way and so one can’t have any sort of discussion with her. She likes to chat with people dropping in and they might not be aware of anything wrong. She has always hated being alone. She has nothing to occupy herself with. She will read the *Observer* but I don’t think it registers. She has been reading the same book for 6 months or more and has only got half way through, yet says she is enjoying it. I occasionally take her for a drive and she loves that. Her only real pleasure is when our son or daughter come. I sometimes wonder, when she behaves more or less normally with other people but with me shows all her difficult sides, whether I am the wrong chap to be looking after her. Let someone else have a go? Yet her lovable side is still there

though it can suddenly switch to the other thing for no good reason. She has great appreciation for the beauty of flowers and trees and can be touchingly sympathetic to others in their troubles. At times very affectionate to me, frequently saying how much she loves me.

I don’t see how any kind of a break for me could be arranged without some cruel deception to my wife. She wouldn’t understand the need and would be thinking why can’t she come too? There is no one I can think of that she could stay with and if we hired someone from an agency again she wouldn’t understand and would be deeply hostile to her.

There are many more minor difficulties, but you will have heard all this stuff dozens of times in other cases. But it is helpful to me to get it off my chest. I really think the only thing is to soldier on and try to keep things calm. But we all know that something is going to happen to bring about a necessary change, most likely a bad fall, and things can only get worse and the time will come when I can no longer manage. So any comments you may have will be helpful and any advice about what we do when it happens. Should we be making a provisional booking at some kind of care home?

**Anissa Baldwin**

### Note from the author

The above was written by the husband of a patient of mine. She suffers from dementia. I feel that it is a compassionate and starkly honest account of life as a carer. As doctors and nurses who deal with such carers and their families perhaps it deserves a wider readership, and we should reflect on how we can help carers more effectively.

### Consent

The family have consented to the publication of this article and all names mentioned have been changed.