

Social care: 'How do others manage without the extra we're able to afford?'

Rosemary Moore, 86, on how her husband Derek's dementia has affected their finances

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Sat 17 Nov 2018 07.00 GMT The Guardian



Rosemary and Derek Moore at home in Ashbourne, Derbyshire. Derek suffers from Dementia and the care costs are becoming a problem to finance. Photograph: Fabio De Paola for the Guardian

Name: Rosemary and Derek Moore

Age: 86 and 87

Income: £44,232 (joint income)

Occupation: Retired teachers (schools and higher education)

Derek and I have been together for 56 years. And they've been very good years.

I went to Somerville, an all-women's college at Oxford, to do philosophy, politics and economics. I got involved in rock climbing where I met my husband in the 1950s, and we married in 1962, moving to the Midlands.

I took early retirement at age 53. Derek retired at 60. We were always very keen on the outdoors, and we used to go on walking holidays, and later went on cruises. We were not extravagant, and we could afford it.

Our total retirement income is £3,686 a month, including £342 of attendance allowance. That means we are very comfortably off by most standards. It was from us both being teachers and having the pensions index-linked.

But Derek's memory started to deteriorate, as he has vascular dementia, which came on quite slowly. About four years ago things started getting quite difficult.

We moved to a bungalow in April last year. Derek started going to a council day care centre once a week. One day I had a carer at home so I could go out. I also found an excellent man to take Derek out for a few hours once a week, and they would go for a walk, have a pub lunch and do the shopping. This is still going on. Between June and December 2017 we spent £5,692 on care, equal to £813 a month. But we could still afford it and have quite a bit left over.

Derek has a long-term health problem, with his prostate, which was being controlled by medication, but at Easter it failed. It meant an emergency trip to hospital and permanent catheterisation. I nearly gave up when I had to cope with the catheter. I'm fortunate to have a son-in-law who lives locally who is a very admirable person. But for six weeks I needed carers in night and morning, which costs a lot. I also had to send Derek to the council respite care centre every few weeks for a few days, so that I could have a break. From May to October we spent £8,342 on care, which is nearly £1,400 a month.

An extra cost has arisen because our local care home couldn't cope with Derek as he was always escaping. Our son-in-law now drives him to another more secure home that costs £100 for the day.

With all the costs, much of our income now disappears, and it's not going to get any better. We have an inheritance which we have left invested. It's there in the event of full-time care home fees. I don't want to touch that until the care home is upon us. But at the current rate we will have to break into it.

How do other people manage without the extra care we are able to afford? I just don't know.

Care availability is very much a postcode lottery. Where we live, it's a nice area, a prosperous part of Derbyshire with a lot of expensive properties. Before, in a poorer district, we were able to find carers who were local. Round here, good carers are as rare as hen's teeth.

I need to look after myself as well, which I think is important. I can now manage with respite care every six to eight weeks. But it's never easy.

When I retired, I wanted something intellectual to keep myself occupied, and did a PhD in early Quaker history. I've written a book on it and am considered something of an expert on the subject. I'm currently doing work on the final proofs of a new book. A further book is in the pipeline.

We live on the top of a hill but with a good bus service. But you do need a taxi to get to the doctor. We don't run a car any longer. You can get a lot of taxis for the price of running a car. I don't regret getting rid of the car in the least.

I have always done our accounts, and I'm computer literate – I've set up an Excel spreadsheet myself.

If anything should happen to me, Derek will have to go into full time care. I'm assuming at some point it won't be our decision.

As told to Patrick Collinson