“Lack of community support puts strain on family carers”

My father, who has dementia, has just passed another major milestone, his 85th birthday. He celebrated his day with immediate family, including his sister, nieces and grandchildren – and what a wonderful day we had. It was made all the more special because dad was able to come downstairs and join us, as mum had bought him a stairlift. Seeing him coming downstairs was truly wonderful, like he had gained a pair of wings and was at last free.

The stairlift attracted much admiration from our visitors that day, including the grandchildren who insisted on taking turns to ride it up and down the stairs. My son thought he was back at Disneyland, even if it was a little slower than the rides he was used to. Considering how much it cost, this stairlift should have come with gold-plated wheels and go faster stripes; however, we were given no choice, pay for it ourselves or dad stays upstairs.

The ongoing costs for caring for people with dementia falls mainly on their families, not only in financial terms but also in health terms. Caring is a full-time commitment and I ask myself who cares for the carers? As a nurse I work as part of a team; at the end of the day I go home and my colleagues take over. When I get in I often collapse on the sofa with a warm drink, but in mum’s case she is all alone with the knowledge that there is no one to come in and take over from her or even make her a cup of tea.

You could argue that she has a carer coming in for 30 minutes twice a day to help, but how much rest do you get in half an hour? And is it enough when you have probably been up half the night? I would love mum to have more help at home, but she would have to pay for it, and already the costs are mounting up with the extra incontinence supplies she has to buy each week including bed pads and pull ups, neither of which are available on prescription.

Sadly, the community nursing team hasn’t turned out to be the support I hoped it would be; I had to fight to keep dad on the virtual ward as they wanted to discharge him. Mum hasn’t heard from anyone for weeks and the antibiotics at home never happened. Dad is still waiting for the community psychiatrist to make a home visit; this has been cancelled twice since December and both times at short notice. Is it any wonder that mum keeps asking does anyone care?

So I ask myself again where is the care in the community and who cares for the carers? Caring is a full-time, physically and emotionally challenging job that many people are doing day in day out unnoticed in the community. Without these wonderful silent heroes our overstretched hospitals would be meeting the challenge of caring for these people. They deserve better and so do their loved ones.

If you know who cares for the carers can you please share it with the rest of us? From where I am sitting I see a postcode lottery in care – and we certainly aren’t the winners.

The author is a nurse who has chosen to withhold her identity to maintain the confidentiality of her parents.

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