

Exercise: A carer's experience

This scenario is a carer's account of two different experiences of the health and care system when her father and then her mother became unwell.

Five years ago my father was diagnosed with Motor Neurone Disease. He deteriorated quickly and my mother needed help caring for him. Sourcing this help was time consuming and confusing. It seemed to involve an endless string of people visiting the house, asking questions and filling in forms. Each professional who visited wanted to start at the beginning and none of them seemed to talk to each other. My father did eventually get support but we were always left wondering what would happen next. He died two years ago at home.

Six months ago my mother had a stroke. After the initial shock we made the decision that mum would move in with me. Mum had been in a stroke unit for three weeks and then been supported by the community health service for three months. The stroke team then said she was as stable as could be expected although they kept some maintenance physiotherapy going. We tried on our own for a while but it quickly became apparent that we needed more help.

Mum was now mobile but only with a frame and couldn't always make it to the toilet on time. Her speech had improved a lot but she still struggled to make herself understood by strangers. This meant she was too embarrassed to go out much and despite us offering lifts she stopped going to church and her local lunch club. When her old mates tried to arrange to visit she fobbed them off with excuses. I felt I had to be with her all the time. I didn't mind getting her up and helping her to bed at night but I really wanted some time back to myself in the day and I wanted mum to have a life outside of our four walls.

This time sourcing the help we needed was different. Mum's physiotherapist made a referral to the local authority and with our permission sent them a lot of mum's details and history. She then introduced us to Lucy, a social worker. Lucy visited one day when Mum's physio was here. Lucy quickly checked she had up to date information then moved onto ask us about what life was like for us since mum's stroke and how we would like it to change. They asked what we felt was important to us and what support we thought might make a difference. She got mum to admit she wasn't happy with the way things were and to try out a few changes one step at a time.

They helped us write it all down in one document which we all had a copy of. They put me in touch with carers support group and worked out a timetable with mum and her mates that meant I got a lot of my day back. A copy was even sent to mum's GP at our request.

I wasn't made to feel bad for asking for help and nor did we have loads of strangers invading my house. After six weeks mum had a busier social life than me. Her speech was improving with use and she was back in with 'the gang'. This meant I was part of her life but not all of it. OK it wasn't like it used to be but it felt like a new normal. Lucy even closed mums case after a review as we were managing so well on our own.

Questions

- What are the main differences in the approach taken by care staff, and in the experience of this carer, towards her mum and dad?
- What are the key elements of an effective whole family approach?