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## WHAT YOUR PATIENT IS THINKING

# Caring is the invisible piece of the stroke recovery puzzle

Chandrika describes the impact of becoming a carer for her mum after she had a stroke

Chandrika Kaviraj

In early 2008 my mum had a severe stroke. She was left with hemiparesis and her life—and ours—changed forever. Part of my mum’s personality went with the cells that would never return. She lost her mobility and experienced changes in cognition, dysarthria, needing emergency dental care, changes in her sight, and emotionalism. I spent every day in hospital with her, and I became the sole carer for a person who had gone from fully independent to needing a great deal of assistance. I felt like I had been pushed off a cliff. Navigating health and social care support systems was not (and is not) easy.

Health professionals felt my mum would do better recovering in her own home, but that meant I had to establish new contacts with pharmacies, spend time making GP calls and seeking referrals, administering medications, maintaining physiotherapy exercises, making meals, running a household, and coping psychologically, while helping my dad come to terms with the upheaval.

### Finding confidence

When my mum was discharged, I felt I had no real contacts with the hospital or in the community to reach out to, and I was isolated. I wanted to define more clearly the significant life changes and challenges we faced for the future, and to get practical advice as early as possible. This task felt like being a juggler on a unicycle with a rapidly deflating tyre, while wearing a sari.

My mum received community therapy, which helped her (and our family) learn to cope. But this ended after six weeks. I needed more support to help navigate long term care and systems. Without this input I felt compelled to take on even more for my mum. I needed to become resilient, gain confidence, and develop advocacy skills and emotional strength when hope had nearly gone. I wish my mum had been given the option of referral for rehabilitation, even years later. I believe being able to set different goals would genuinely have helped her confidence and mental wellbeing.

### Balancing being active with processing

The changes in my mum left her feeling hopeless and bewildered. Even now, I can sense her sadness. She has gone from being an independent, active, lively woman to a “helpless person” as she describes it. The impact across our family has been considerable. My father and sister found it difficult to comprehend the physical and psychological transformation in my mum. As a family we were always encouraged by therapists to be active in all facets of my mum’s

recovery, but I often felt people didn’t “get” that we were also processing everything too.

I wish I had received more guidance on how, as my mum’s carer, I could empower her. Especially in helping her do meaningful tasks, understanding her emotions, learning how and when to motivate her, and where to find help for issues such as pain and spasticity. Being signposted to support and information would have been appreciated. For those of us spending a significant part of our lives caring, we also need psychological support to maintain our mental and physical health. We need help in being the long term support to stroke survivors.

#### What you need to know

- Stepping into the role as a carer is hard. It can feel overwhelming and intimidating
- From the outset, be clear with carers about what they are expected to take on when their family member leaves hospital
- Suggest or discuss where carers can go for advice and support with longer term care

#### Education in practice

- What support or resources could you share with someone who has become a carer for a family member?
- At what stage might you discuss with family members what they can expect when their loved one is able to leave hospital?

#### Additional information

- Stroke information pack for families. <https://www.sth.nhs.uk/stroke/pil34.pdf>
- A carer’s guide to stroke. <https://nichs.org.uk/assets/resources/ACarersGuidetoStroke.pdf>

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