

Emily Woodruff did not have a good year. After her husband of 60 years died in January, she became lonely and increasingly confused, and in June, she had a stroke, leaving her with right-side paralysis and limited speech. Eating was so difficult that doctors inserted an abdominal feeding tube. In July, she was discharged from hospital to a complex continuing care unit. In September, her son asked me to check on her care.

A long journey back:

Improving Emily's care



By Pat M. Irwin

What I found was appalling: the elegant, loquacious lady I had known was alone in a bare room, curled in a fetal position, staring at a silent TV screen. Her hair was flat and oily, her hospital nightie reeked of urine, and her eyes were dull and lifeless. She did not respond when I held her hand and spoke to her. Three months ago, she had left the hospital in far better shape. What had happened after the move to complex care?

Investigating her care

My first task was to meet with Emily's care team: the attending physician, charge nurse, physiotherapist, occupational therapist, speech-language pathologist and social worker. I quickly learned that this was a non-maintenance unit with no mandate to even keep Emily as well as she'd been at admission. Since no goals for Emily's improvement had ever been discussed, this fact had never emerged, and her decline had been considered inevitable.

Care Tip Before someone who has had a stroke can be released from hospital, the rehab unit will define realistic goals. Be sure those goals can be met at the new facility where you parent is placed after discharge.

My next step was to reconnect with the hospital rehab staff who had helped Emily after her stroke. Could they help her get back to where she'd been when she was first discharged from their care? The attending physician was asked for a referral back to the hospital's seating clinic, where the occupational therapist arranged for Emily's wheelchair to be adjusted to alleviate her bedsores and deteriorated muscle tone. The physiotherapist designed exercises to address Emily's spasticity and to increase her flexibility and strength. Both therapists provided referrals to private therapists for follow-up assistance.

Care Tip Stay in touch with the rehab team who worked hard to help your parent. If a formal referral cannot be made, ask them for suggestions for private therapists. Use their expertise to assess options and set realistic goals for this stage of your parent's recovery. Work with them to monitor your parent's progress.

Finding an unconventional solution

I realized that a non-hospital environment was essential for Emily's mental and physical well-being. While all expert advice indicated long-term care, her son and I found a retirement home to accommodate her needs.

Care Tip

Be creative and persistent with housing and care solutions. Emily's son and I analyzed Emily's medical needs and found a way to meet them within a non-institutionalized setting.

Emily was delighted to be in a private room surrounded by her own furniture. She was also recovering her verbal skills thanks to a speech-language pathologist. Emily was disappointed, however, by being confined to her room because of the feeding tube, and she missed socializing with others at mealtime. Although her son and I were told the feeding tube was permanent, we asked the speech-language pathologist for a swallowing study. To everyone's delight, Emily passed the tests and began a puréed diet of real food. Yes, there was a risk of choking—a suction machine was purchased—but the risk was offset by Emily's keen desire to graduate from tube feeding and by her family's concurrence with her wishes for "quality of life."

Care Tip

Respect expert advice, but don't be afraid to research and suggest alternatives. A "managed risk" may be justified by the quality of life.

Returning to her old self

By Thanksgiving, Emily was starting to resemble her old self, but she was still depressed and uncommunicative. We worked with the staff on a routine that got her out of bed, dressed, and into the wheelchair to attend scheduled programs. A companion was hired to talk with Emily one-on-one and to take her on outings and to weekly hair and manicure appointments.

Care Tip

1) Anticipate the depression and frustration that will occur when your parent realizes that, despite all efforts, there will still be limitations.

2) Your mom may not look or act like she used to, but you can honour who she was and still is. Help her deal with the new reality for all of you; after all, she's still your mom.

Six months later, Emily returned not to her pre-stroke self but to someone any friend would recognize. It was a long journey for her and for her adult children. Emily, welcome back. ●

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Anonymous

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