

# Stroke affects the whole family, and here's how to help keep it together

17 May 2021, by Casey Morris



When Carol Coulther's husband, Rich, had a stroke, her teacher instincts kicked in immediately. She began writing down everything his doctors said to make sense of what happened and what he would need in his recovery.

Coulther's instinct to document everything was spot on, according to advice from Dr. Amytis Towfighi, director of neurological services and innovation for the Los Angeles County Department of Health Services and associate professor of medicine at the University of Southern California in Los Angeles.

Towfighi, who has written a book about how to recover from and prevent strokes, suggested asking questions about the type and cause of your loved one's [stroke](#), as well as their [risk factors](#) and special equipment needs when they return home.

"The stroke survivor should feel empowered to manage his or her condition—learn how it happened, what to do to prevent it from recurring,

and how to set realistic short-term goals," Towfighi said.

Feeling encouraged is crucial. In addition to keeping track of doctor conversations, Coulther took photos and videos of Rich's progress and kept notes their daughter left in his hospital room.

Having those records allowed her to show him how far he had come when he felt frustrated.

"My husband's physical disabilities were huge. It legit was three weeks before he could move one finger, so you lose track and you think, "My gosh, I can't do anything," Coulther said. "If he was discouraged, I could say, 'No, look, this is what you did. Now you can actually stand, and now you can do this.'"

Documenting everything gave her something to focus on, too.

"It helps you feel like you have some control over something you don't have any control over," Coulther said.

The stressful aftermath of a stroke can cause connections to fray. A review of 78 studies published in the American Heart Association journal *Stroke* in 2009 found up to 54% of families said stroke had a negative impact on their relationship.

The risk of depression also is high. Stroke survivors are 50% more likely to develop depression during their recovery than [heart](#) attack survivors, according to research published earlier this year in *Stroke*. Not only is depression correlated with other health troubles—including anxiety, insomnia and fatigue—it is associated with worse outcomes and increased risk of death among stroke survivors. It also adds more strain to families.

Towfighi, who led a 2016 AHA scientific statement on post-stroke depression, advises caregivers to

look out for signs of depression in their loved one and notify the patient's doctor if they believe their loved one is at risk. Therapy and medication can help stroke survivors overcome depression and alleviate the pressure it puts on relationships.

Taking the process one step at a time helps manage stress levels as well.

"It's got to be one day at a time, one week at a time, and not, 'How will he be a year from now?'" Coulther said.

One of the biggest mistakes Towfighi sees caregivers make is "trying to do everything for their loved one and letting their loved one assume the sick role and stay in bed."

While rest and patience are important, exercise repetition and setting short-term goals are also important to regaining strength and independence.

Families who have local support systems—as the Coulthers did in their Rockaway, New Jersey, community—should be honest about what they need, Coulther advised.

When she explained what she and her daughter really needed while her husband was in the hospital, whether that was [potato chips](#) and wine or someone to help out with yard work, people were happy to pitch in.

"People were like, 'Oh gosh, there's something I can do,'" Coulther said.

She also recommended looking for support groups through local hospitals and social media groups. These provide a place to get advice and connect with families who are going through similar experiences.

Self-care and boundaries also are critical.

"I think a really important thing for caregivers, especially in the beginning, is you have to not listen to people that say, 'You have to take care of yourself, go get a pedicure, go do this.' Maybe you're not ready," Coulther said. "Maybe it is taking care of myself to read a book on the couch, as

opposed to me stressing about leaving. People have to do what's right for them."

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