



SC FEATURE STORY

When Loved Ones

LASH OUT

Just because a survivor may not be able to physically hit someone doesn't mean they can't hurt them. **by Jon Caswell**



“Winter is the worst, because then he’s cooped up all the time, so he throws a tantrum almost every day,”

said Jan D., age 59, of her former fiancé and current housemate Harvey, age 65 (not their real names). The couple had moved in together with plans to marry, but then Harvey, a contractor, had a left-hemisphere stroke. Beyond right-side hemiparesis that prevents him from working or driving and some speech difficulty, the stroke also changed his personality. “Before the stroke he had a quirky sense of humor that was entertaining, but that ‘humor’ is now sarcastic, biting, insulting and intentionally hurtful.”

“This situation of survivors abusing caregivers comes up way too often,” said psychologist Barry J. Jacobs, Psy.D., director of behavioral sciences for the Crozer-Keystone Family Medicine Residency Program in Springfield, Pa., and author of *The Emotional Survival Guide for Caregivers* (Guilford, 2006). “Stroke changes the way the brain works. It can cause neurological damage that leads to decreased function that makes it more likely that the survivor will lash out.”

Defining Abuse

Many people equate abuse with physical violence. Therefore, it might seem counterintuitive that a stroke survivor, who may have multiple physical and cognitive deficits, could harm anyone. But survivor-on-caregiver abuse is typically verbal or psychological. Just because a survivor may not be able to physically hit someone doesn’t mean they can’t hurt them.

Neuropsychologist Dr. Mark Sandberg, a diplomate in rehabilitation psychology and staff physician at the VA Medical Center in Northport, N.Y., defined abuse this way: “Whenever a caregiver feels the survivor’s behavior is designed to hurt, diminish or unnecessarily control them, they should consider that abuse.”

Why It Happens

There’s no way to predict if or how a survivor will become abusive after stroke. “While people with left-brain strokes tend to be more depressed, people with right-brain strokes can be more impulsive,” Dr. Jacobs said. “Both depression and impulsivity can contribute to lashing out.”

“It’s usually the interplay of pre-stroke psychological and stroke-related physiological changes that bring about behavior that could be considered abusive,” Dr. Sandberg said. “Having said that, a person who sustains a right-hemispheric stroke has tendencies toward diminished awareness, which may create insufficient concern about situations as well as impulsive and inappropriate responses. Those types of changes predispose a person to react poorly to frustration, which in turn may lead to behaving in ways that could be considered abusive.”

Typically, survivors lash out at caregivers for two reasons, according to Dr. Jacobs. First, because of a loss of impulse control, which often happens with frontal lobe damage, and makes survivors more likely to lash out when they’re frustrated. (Frontal lobe injury is also associated with loss of empathy.) And second, survivors who are frustrated at their losses and clinically depressed may take those feelings out on those closest to them.

“When Harvey goes off on me, I feel worthless, like what I think

Nearest Target

Ella Parsons, age 70, knows about this firsthand. Her mother, Leona Mortensen, had seven strokes and numerous TIAs over 18 years before she died in 2007 at age 90. “With each stroke she got meaner and meaner,” Ella said. “After the fourth one, I had to place her in assisted living, and when I would visit, she was ready to fight before I could even say hello. She didn’t want to converse, she just wanted to rant. She was always hateful and accusatory and belligerent with me, but she never acted up with anyone in the facility, never argued with the CNA (certified nursing aide).” Her fifth stroke left her with aphasia, but that didn’t make her any more docile



Ella Parsons (left) and her mother Leona Mortensen share a happier moment.

or easy to get along with. “Sometimes she would reach out to hit me or give me a dirty look or make a face like she was going to yell at me.”

Jan has also experienced verbal abuse. “Harvey can lose his temper with me over the

most ridiculous things. For instance, last winter he threw a tantrum because I would not go get garlic when it was 20 below zero. Another time it was because I bought the wrong kind of cat litter. Then I bought the wrong size. When I got the right kind in the right size, I bought it at the wrong store and paid too much. With each ‘mistake’ he got completely out of control.”

Our experts’ advice about this type of behavior is not to tolerate it. “First and foremost, leave the room,” Dr. Jacobs said. “Caregivers have to be very clear that they will not tolerate being abused. The more a caregiver puts up with maltreatment, the more they encourage the survivor to behave that way.”

Before and After

Often, how survivors and caregivers related to one another before the stroke is a factor in how they relate afterward. If they had a rocky relationship before, their post-stroke relationship may be rockier still. After all, frustration, depression, grief and disappointment coupled with physical disability rarely bring out the best in people.

Even before his stroke, Harvey could be difficult and overbearing and didn’t seem to care much about other people, Jan admits. “Even then I thought he was overly opinionated

and seemed to need to be the center of attention all the time,” Jan said. “He definitely had a temper, but he could stop himself before it got out of control. Now it’s impossible to have a normal conversation with him because he cuts off whoever is speaking. He only wants to express his opinion and doesn’t seem to care what anyone else has to say. With his family, he constantly brings up past issues and provokes arguments.”

Personality styles are another factor in how people respond to frustration and disappointment. For instance, a psychologist might label a person who doesn’t care about the feelings of other people and even exploits them as a narcissistic personality; an antisocial personality is characteristically insensitive, irritable and aggressive and may disregard their own safety or that of others. “The association between personality style, area of neurological damage brought on by the stroke and how the loss of function is being experienced by the survivor are all critical to consider in understanding why certain behaviors are present and how best to treat issues that might require intervention,” Dr. Sandberg said.

How It Feels

“One shorthand definition of anger is that it’s depression turned outward,” Dr. Jacobs said. Often it is used to control another’s behavior by causing them to feel guilty.

Jan described her feelings this way: “When Harvey goes off on me, I feel worthless, like what I think or feel makes no difference, like I’m nobody, like no matter how much I do for him, it’s never enough.”

According to Dr. Jacobs, Jan’s feelings reflect classic victim thinking: ‘If only I had done it better, he would not be acting this way.’

“What happens in abusive relationships is that the one being mistreated feels responsible for the mistreatment. It often takes women years to leave an abusive relationship because they continue to believe that if they could change, everything would be all right,” Dr. Jacobs said.

But Jan is not doing herself or Harvey any favors by putting up with his behavior. “Staying with an abusive survivor and allowing him to be abusive doesn’t help the survivor,” he said. “People should be held to a certain standard of behavior, and when we don’t hold them to that standard, we do them an injustice.”

Jan has threatened Harvey with putting him out of her house and giving him back to his family. “When I do, he tries to put the brakes on his tantrum, but he just doesn’t have enough self control to stop. He panics when I threaten to call his sons to intervene — he doesn’t want them to know he’s out of control.”



Get the Doctor Involved

Dr. Jacobs emphasized that medical intervention is key to improving the caregiver's situation. There are psychiatric medications that help people gain control over their impulses as well as for depression. "The best thing a caregiver in this situation can do is get their loved one to a doctor because medication can help in most of these cases," he said.



Dr. Jacobs (left) and Dr. Sandberg believe support groups are beneficial.

Jan has suggested this to Harvey, but he isn't interested. "I've talked about his behavior with his doctors," she said, "and they are more than willing to refer him for psychological

evaluation and medications. He even had one tantrum in the doctor's office, but he refuses to take the doctor's advice. He doesn't even acknowledge his behavior is a problem. It's always someone else's fault. He feels it's his right to say whatever he wants, however he wants to, and if you don't like it, that's your problem."

Grief Has a Role to Play

According to both doctors, grieving losses is an important aspect of recovery after stroke. Since both parties in the relationship have experienced losses, both people have to grieve. "Survivors who are able to grieve and thereby accept their losses are less likely to lash out," Dr. Jacobs said. Caregivers also benefit from grieving the loss of the person they knew; accepting the survivor as they are now insulates them when the survivor lashes out.

"Working through the feelings of loss is important," Dr. Sandberg said. "Recovery from stroke includes an acceptance of the limitations that have resulted. Through that acceptance, both survivors and caregivers can realize that new opportunities and possibilities are available."

Ella Parsons found it difficult to accept the person her mother had become, especially since she only acted out toward Ella. "She was always good with the people at both the facilities where she lived, but whenever I showed up, all she wanted to do was fight." Those attacks were so painful that Ella reduced her visits to once a month, but that left her feeling guilty. "I would come home from seeing her and just cry."

For a long time Jan found it difficult not to take Harvey's outbursts personally, but as she has grieved the loss of

the relationship they once shared, she's found it easier to disengage. "I no longer react by feeling guilty," she said. "I understand that a lot of it is the result of the stroke and his forced retirement. I realize that the relationship we had prior to the stroke is gone. He simply doesn't care what I think or feel. He doesn't care one bit how his stroke has affected me or the rest of his family. I don't like or respect him so his negative opinion of me no longer has the power to hurt me."

Support Makes a Difference

Both Jacobs and Sandberg felt that caregiver support groups benefited caregivers, whether or not they are in an abusive situation. "The emotional support and problem-solving opportunities that come about in support groups are very helpful," Dr. Sandberg said. "It's great to know that your feelings and concerns are not unique and that you are not alone."

Ella had a kind of informal caregiver support group among friends in her aerobics class, one of whom was dealing with an extremely ill husband. "We would talk after class," she said. "We called it our 'psychiatric treatment.'" After her mother passed last year, Ella saw a therapist for seven months. "That was very valuable for me because she helped me get through the anger I felt and the sadness that the last two years of mom's life were so difficult. I think if you can get some kind of support while you're going through it, that's the best. It would have helped me so much if I'd known beforehand what was likely to happen."

Unwilling to put Harvey out, Jan copes as best she can. "I tried reason at first, but then I realized he has the emotional maturity of an eight year old, so reason seldom works. Arguing back only exacerbates the situation. Sometimes I just leave the house for a few hours, or simply don't respond at all, but that really gets him going — he can't stand when there's no reaction."

"If a caregiver can see the survivor's anger as a manifestation of the stroke," Dr. Jacobs said, "then they don't have to take the name calling and the anger personally, and it doesn't hurt as much. That doesn't mean they should excuse the behavior. They should require them to get help for their behavior. If a caregiver feels she is being mistreated, she should seek some sort of outside help immediately by reaching out to a physician or a local support group. And she should talk to other family members about getting some relief." **SC**

Editor's Note: For a list of questions that may help you better assess and make decisions about your situation, visit www.strokeassociation.org/strokeconnection.