DUNCAN WALKER/ISTOCKPHOTO

Who's There?

When stroke or Alzheimer's changes a person's behavior, caregiving can become extreme. Here, experienced caregivers, patients, and experts share their stories and advice.

BY STEPHANIE STEPHENS

Hands gripping her throat, Jacqueline Marcell's elderly father, Jake, raged at his caregiver daughter for switching on a television movie channel he didn't remember ordering. She finally broke free and frantically dialed 911.

After the incident, police took Jake to a psychiatric hospital, where he morphed back into a teddy bear. Eventually he returned to his chaotic, homebound life, struggling but failing to care for his elderly wife, Mariel. And Marcell was left once again to pick up the pieces for a father whose behavior was frequently and intensely out of control.

Both her parents had been diagnosed with Alzheimer's disease, says Marcell, though not soon enough. She's since become a passionate and refreshingly humorous advocate for caregivers, through speaking engagements and as the author of *Elder Rage, or Take My Father Please! How to Survive Caring for Aging Parents* (Impressive Press, 2nd edition, 2001). She's on a mission to assure caregivers they have company—plenty of it—and counsels them to take care of themselves lest stress take its toll.

"I was undergoing the most incredible stress of my life and catching every cold and sore throat possible. I felt like my immune system wasn't working as well as it should. Later, I was diagnosed with invasive breast cancer and underwent six surgeries. Was the fact that I wasn't taking care of myself directly related to my breast cancer? It's my opinion that it was." (Studies

After Marcell broke free of her father's grip, police took him to a psychiatric hospital, where he **morphed back** into a teddy bear.

done over the past 30 years of the relationship between psychological factors, including stress, and cancer risk have produced conflicting results. Stronger relationships have been found between psychological factors and cancer growth and spread than between psychological factors and cancer development.)

"Your life and theirs comes apart," she says. "You can't trust them, a child in an adult's body, and often they don't trust you either."

Her father called her "every name you can imagine." She wept consistently for a year. Still, Marcell reviewed her list of gratitudes daily—things for which she was grateful—and staunchly bore her "emotional shield" when confronting the worst moments. Her own struggle may be more extreme than what many of us will experience, but the wisdom she's gained is universally applicable.

"Every person who has ever lived has undergone the heartache of those who came before us getting old, getting sick, and passing away," she says. "We understand it intellectually, but when it happens to our loved ones, no words can prepare us. We somehow think we're the only one who's ever experienced it."

Wendy Sessler understands, for she and her mother Mary Morgan have also walked this lonely but well-traveled road. Morgan, age 69, of Kill Devil Hills, NC, exhibited no apparent risk factors when she suffered a massive stroke in 1996. A clot in her brain stem "affected everything," she says, resulting in behavioral changes.

"It was like an alien had overtaken my body," says Morgan, who also cathartically authored her story, the book *Like a Bolt* (LAF Publishing, 2004). Lacking feeling on her left side, she uses a power wheelchair and walks "maybe 10 feet if I hold on to something. I can't keep my balance."

Unwelcome psychological changes have been no picnic. "It's pretty horrible," she asserts. She's chronically depressed and knows why.

"You wake up and half of your body's turned to JELL-O."

Her devoted daughter, then 32 and happily married with three children, selflessly returned to help her irritable, frustrated, and frightened mother. She remembers Morgan needing things done "right now!" and using few words to say so, because it was easier.

"When she made me upset, I reasoned that it wasn't really 'her.' Taking care of her was just what I had to do," Sessler says.

A "struck-down" and "fragmented" Morgan says she didn't mean to shout.

"There was so much anger, yet I was in the background 'listening' with a detached feeling: mouth running, brain just going on, thinking I'd lost control of everything. A statement would come out of my mouth, and I'd think: 'Where did that come from?'"

Reacquainted with her pre-stroke identity eight years ago, she says, "It was the first time I referred to myself as 'Mary.' I still look like her, have a lot of her parts, but I'm not her." Morgan knows many caregivers also struggle to identify their survivor as the person they once knew.

"This condition is as new to the affected as it is to you. Understand their difficulties and know that loving them is something that you can't overdo," Morgan says.

Cognitive dysfunctional changes in behavior are distressing and can be dangerous, whether caused by stroke or the progression of Alzheimer's. Ignore them and they won't go away.

Antipsychotics in Dementia Treatment

An increased risk of death has been reported in patients with dementia receiving antipsychotics. A three-year study led by Clive Ballard, M.D., of the Wolfson Center for Age-Related Diseases at Kings College in London, showed that only 30 percent of demented patients on antipsychotics were still alive at the end of 12 months, compared to 59 percent of those who took a placebo. Researchers found that the risk increases substantially after more than a year on the medications.

The British study is not the first to recommend judicious use of antipsychotics among patients with dementia.

"Antipsychotics do have benefits for the psychotic patient who cannot be redirected," comments Dr. Karlawish. "The decision to use them has to be based upon very careful understanding of whether known risks are worth the potential benefits of treatment. A clear, measurable goal should be set regarding benefits and if that goal is not achievable, the medication should be stopped."

For Jacqueline Marcell, the risks were worth it. "If doctors had not utilized these medications," she says, "I could not possibly have controlled my father. If medication use shortens life, it is my opinion that the patient could also shorten others' lives if not correctly managed."

Dr. Karlawish cites FDA black box warnings noting increased risk of death and contra-indicating use of the drugs for control of agitation with Alzheimer's dementia. Other potential problems, he says, include difficulty with walking, exacerbated risk of falls, increased risk of developing diabetes, and increased risk of death from cardiovascular disease.

Your Coping Toolbox

TO HELP THE PATIENT OR LOVED ONE:

- Believe it when that person says, "It hurts."
- Redirect and diffuse aggression.
- Offer single choices of meals or other options. Don't force.
- Explore the healing power of touch.
- Minimize noise and distraction.
- Tune into signs of possible patient self-harm or suicide.
- Understand the condition, treatment (including medications), and recovery prognosis.
- Be creative: ask questions, play games, decorate with photos.
- Utilize adult daycare and social worker or volunteer visits.
- If behavior changes become unmanageable, seek professional help.

TO HELP YOURSELF :

- Don't take "it" personally.
- Walk, exercise, meditate, pet your pet, get a massage, do yoga.
- If your mood, thoughts, or behavior nosedive, seek professional help.

FINDING HOPE TO COPE

"If you don't understand how to cope, you'll flounder," Marcell says. "Seek out the right doctors and the right medications for your loved one. Take it on like a project."

Remember too that the resulting behavioral changes are due to the disease or brain injury rather than the personality. Don't take the changes personally, counsels Barry J. Jacobs, Psy. D., clinical psychologist, family therapist, and author of *The Emotional Survival Guide for Caregivers* (The Guilford Press, 2006). Caregivers can learn to stay cool when patients react to feeling threatened, misinterpret what's happening, or become confused or agitated.

Still, managing paranoia, increased aggression, or psychosis can perplex and overwhelm even the most seasoned caregivers, including professionals. With Alzheimer's, it's essential to understand the progressive stages of the disease, says Dr. Jacobs. Healthcare professionals usually describe three broad categories (sometimes broken down into seven more detailed categories); ask yours to explain how they apply to the person you're caring for.

In the early stages, the person comes to grips with the diagnosis and exhibits recent memory loss, often with depression or apathy. Caregiver supervision, including necessary reminders, may sustain precious patient independence.

Moderate/middle stage patients may be very frightened, agitated, confused with misperceptions, exhibit rambling speech, and get lost in familiar settings. Obvious emotional and behavioral problems are worsened by stress or change. Caregivers will want to provide orientation with predictable, secure routines that avoid over-stimulation.

In severe/late stages, the patient abandons self-care, is generally incapacitated with delirium or hallucinations, and becomes confused about past or present.

"Then even the most devoted caregiver has a very hard time day in and day out," says Dr. Jacobs.

To lighten the load, he advocates locating resources like home health aides, support groups, and government services—locally or online—and emphasizes that knowledge is power when it comes to brain injuries such as stroke. Neurologists can delineate the stroke's severity and location in the brain, along with how both factors affect memory, reasoning, vision, motor skills, and behavior. Neuropsychological testing can paint a clearer picture of current and future cognitive strengths and deficits.

"You'll have a pretty good idea of where they're likely to be over time and what kind of compensatory strategy everyone must adopt," says Dr. Jacobs.

Temper flares are common, Dr. Jacobs says, but not every survivor becomes a brute. Instead, a patient may react slowly to stimuli, manifest little emotional expression, be seemingly unresponsive, or go from laughter to tears in seconds.

Marriages and partnerships may also be at risk, Dr. Jacobs notes. In fact, many simply don't survive the tumult caused by stroke or other major neurological problems. In June 2009, *The Journal of Clinical Nursing* reported that after a stroke, sexual relationships were significantly affected, gender roles became blurred, and feelings like anger and frustration were confounded by a lack of independence and ongoing fatigue.

MITIGATING AGITATION

Agitation is a common behavior in people with dementia, and it can have a broad range of meanings, says Jason Karlawish, M.D., of the University of Pennsylvania Health System, Division of Geriatric Medicine, where he is Director of the Alzheimer's Disease Center's Education and Information Transfer Core and Associate Director of The Penn Memory Center. "The patient wants to tell us something."

Often caused by fear, fatigue, or something bothersome in the environment, agitation may also be spurred by an unmet need. Medication might be required to quell it. In the event that the person manifests psychosis—loss of contact with reality—an antipsychotic may be prescribed. Antidepressants might be prescribed for depression or anxiety, and "disinhibition"—the inability to control impulses—may require mood stabilizers.

> “It was like an alien had **overtaken my body**,” Mary Morgan says. “A statement would come from my mouth, and I’d think, ‘Where did that come from?’”

(See box, “Antipsychotics in Dementia Treatment,” page 27.)

Beyond medication, though, caregivers can help reassure an agitated person and “redirect” or channel behavior in a new direction without flippantly minimizing the person’s suffering, says Dr. Karlawish.

Example: “Don’t say, ‘Oh Mom, my memory’s not that good either.’ Acknowledge that it’s frightening and say, ‘I’m here for you even if you do have a memory problem. You still have a great smile and a sense of humor.’ Then move to another topic.”

A physiological complaint may also prompt agitation, Dr. Karlawish says.

“A parent who understands a child’s cry knows when it’s not a good one,” and astute caregivers develop similar radar. Unmet medical needs can include infection, bowel impaction, or simply acute pain. Therefore, it’s critical to know when “something’s different.”

Unfulfilled psychosocial requirements such as boredom from sitting all day may be remedied by attendance at adult day care. However, a change in regular patient activities should still respect what’s already in place.

“I always try to establish a predictable routine for patients—getting up and dressed, bathing, eating meals,” says Martha Lentz, owner of Personal Health Care Solutions in Charlotte, NC. Lentz, a geriatric care manager, supervises clients with neurological conditions. Like others in this tight-knit caregiver community, she freely shares successful strategies.

When confusion or agitation set in, she calmly redirects client attention without being challenging. For instance, Lentz was falsely accused of being the “girlfriend” of a female client’s husband. The gerontologist reiterated that she was in fact a cousin and shifted gears by inquiring where the client “had been lately.” The response led to pleasant discussion of the client vacationing in Florida as a child with her parents, thus diffusing potential conflict.

An 18-year caregiver, Andrea Allen, also of Charlotte, avoids making strict demands of clients. Instead, she treads softly and makes suggestions.

“Talk to them as though they’re a real person instead of someone with problems,” she says. “Don’t be so quick and definitely don’t force.”

Marcell’s parents would ask certain questions over and over again. To deal with it, she wrote answers to these common questions on file cards. Then, she would ask her mom and dad the question before they did. It became a kind of cognitive exercise, a game that they actually enjoyed.

Since people with dementia may have difficulty determining the date and time, Marcell suggests that caregivers “go with the flow and live in the reality of the loved one’s moment.” When asking their age, “know that they may be many ages in a day. Remove mirrors and instead surround them with photos of their past years.”

Mary Morgan implores caregivers: “Please don’t assume you know what the stroke survivor is thinking. Listen and pay attention. If the survivor says ‘that hurts,’ believe it.”

She also advises keeping noise and distraction at a minimum, both of which “put the survivor’s brain in the ‘blender mode’ and prevent focus on one task.” Offer meals without too many confusing choices and present options singly: “Do you want beef? Do you want chicken?”

Watch for inklings of possible survivor self-harm. “When you’re vibrant, the life of the party, and suddenly you don’t go to the party any more, it’s bad,” Morgan says. “You were once respected for your intelligence, and now nobody thinks you have any. Reassure the survivor that ‘You’re important to me. I want you to be around.”

Of course, for caregivers to “still be around,” they have to take

JESSICA JONES PHOTOGRAPHY LTD/ISTOCKPHOTO

care of themselves first, Marcell insists: “If you go down, you can’t help, so be Number One. Take a walk or a hot bath. Get a massage. Know that if your loved one were totally cognizant, he or she wouldn’t want the child to have this much stress.”

Most important, touch and hug the survivor. “It’s amazing how the whole body just lights up,” Morgan says. NN

Stephanie Stephens’ mother is entering late-stage Alzheimer’s.

For more information on dimentia, see Resource Central on page 36.