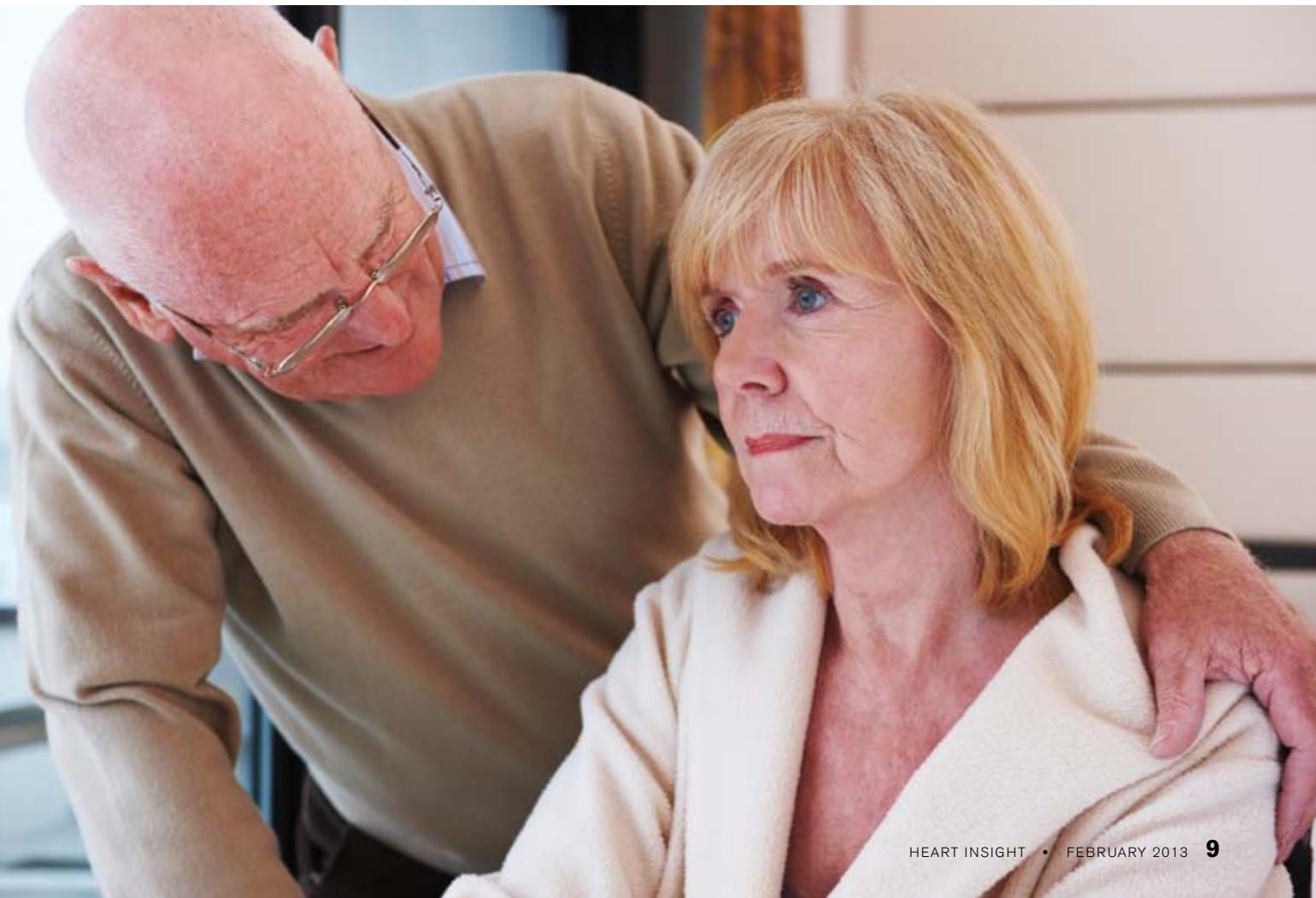


# CHAPTER TWO

*Coping with the loss of your loved one's former self*

BY CAROL PATTON



In 2004, Amy Atcha knew her brother, Jeff, would never be the same. At age 42, he had suffered a severe heart attack, resulting in irreversible brain damage.

"It hit me right away," recalls Atcha, owner of Customized Caring in Hanover Park, Ill. "The first time I saw him in the hospital bed, that vacant look in his eyes, I said, 'Wow, that's not the person I know.'"

The man who was once an economic analyst who enjoyed skydiving and African safaris now needed help with daily chores like dressing and bathing. Amy knew that Jeff, her real brother, was gone.

"I cried, let it out, talked it out and yelled it out," she says. "There was a lot of self-reflection. There were a lot of tears, a lot of crying."

Life-altering diseases or conditions pose a variety of challenges to patients and their families. Sometimes, they can rob patients of their self-identity. Whether it's due to chronic pain, diminished physical or mental abilities or even the powerful side effects of their medicine, some patients are never the same people they used to be. Family members, especially those who care for them, are suddenly faced with an individual whose personality and abilities have dramatically changed. How do they deal with this stranger in their lives and, just as important, how do they mourn the loss of their loved one who no longer exists?

## FORWARD FOCUS

It's fairly common for family caregivers to encounter this situation, explains Rebecca Daniel-Burke, Ph.D., director of special projects and career services at the American Counseling Association who has also counseled patients at agencies and in private practice for more than 20 years.

"The most important thing you can do is create a new story," she says, explaining that people tell a story about their current lives and future plans. "The story used to be we went running, went on long weekend trips, kayaking in the Amazon, all of this exciting stuff. The new story has to change because you can't do these things anymore."

But the new story can still be positive, she says. Search for simple activities that genuinely interest you, that may have been placed on the back burner. Start movie night. Frequent your favorite restaurants or get carry-out. Even consider taking a class at your local community college. It's these collective, small moments—not the once-in-a-lifetime European vacation—that add real value to your relationship and quality of life.

In the meantime, expect to experience the following three stages of loss, a model that was developed by the Alzheimer's Association, Daniel-Burke says. The first stage is shock over the dramatic change in your loved one's physical and mental or emotional condition; sadness when grieving over the person your

loved one used to be; and recovery, the stage where you gather strength to accept your current situation, move on and create a new story.

During this time, consider joining a local caregiver group for support (see *Lean on me* below). If none exist in your community, she suggests developing your own by placing an ad on your local craigslist.

Just as important, let go of the past. "Spend time with the old story, bringing it back every now and then," Daniel-Burke says, adding that it can also be healthy to seek therapy or set aside some private time to cry. "Pay homage to the way things used to be instead of trying to forget about them [so you can] move on to your second story."

However, patients aren't the only ones who typically change. Illnesses usually present growth opportunities for everyone surrounding the patient. In many cases, caregivers redefine themselves by the experience, she says.

"Maybe when people talked about who you used to be, they wouldn't use the word compassionate," says Daniel-Burke. "Maybe that's changed and there's a new definition of who you are as a caregiver and human being."

## SEEING IN THE DARK

A big part of the grieving process involves changing perceptions. Although caregivers mourn in different ways, they're typically in so much pain that they become blinded, not fully realizing what their loved one can still offer, says Alina Sosa-Perez, a licensed clinical social worker at Leon Medical Centers in Miami, Fla.

## Lean on me

Support groups for caregivers can help you feel less alone as you care for a loved one. Call your local hospitals to see if they have support groups in your area, and visit these websites to help you find support groups online.

- Family Caregiver Alliance Online Support Groups [caregiver.org/caregiver/jsp/content\\_node.jsp?nodeid=347](http://caregiver.org/caregiver/jsp/content_node.jsp?nodeid=347)
- National Family Caregivers Association Family Caregiver Forum [thefamilycaregiver.org/ed/bb](http://thefamilycaregiver.org/ed/bb)
- SupportGroups.com [caregivers.supportgroups.com](http://caregivers.supportgroups.com)
- Today's Caregiver Regional Resources [caregiver.com/regionalresources](http://caregiver.com/regionalresources)

## Relationships don't require a lot of hoopla to be meaningful. What makes them worthwhile are moments of comfort and mutual, positive respect for each other.

"You [feel] the loss and [sadness] about that loss," she says, adding that by reducing your expectations of what your loved one can and can't do, you can better adjust to your new circumstance. "Work on [changing] your own perceptions and start appreciating the strength the person still has ... the positive they can offer. It's almost like the light and darkness working together."

Likewise, it's also important to be proactive instead of reactive. It can help you avoid perceiving every problem as a crisis or placing yourself in the position of being overwhelmed by your current situation.

"You lose track that the person is still there and has something to offer, whether it's a smile, a [kind] word or gesture," Sosa-Perez says. "Don't play the role of victim. By being proactive and not being a victim of circumstance, you [may] have strength you didn't know you had."

### RECLAIMING HAPPINESS

When illness strikes, no two patients react the same. After facing death, for example, some experience an existential crisis or wake-up call and completely change their lives by engaging in reckless activities, or in some cases, divorcing their long-time spouse, says Barry J. Jacobs, PsyD., psychologist and director of behavioral sciences at the Crozer-Keystone Family Medicine Residency program in Springfield, Pa.

Others may become more timid, fearful to try anything new, or begin cherishing their relationship more than they ever did in the past. Despite such significant personality changes, Jacobs says most families are able to negotiate the changes and move their relationship forward.

One approach for caregivers is to find the silver lining in the storm cloud, he says. What can you still appreciate or love about the person? Are there things about the illness that perhaps make your loved one a better person? What aspects of your relationship are really worth savoring?

"People have to literally think it through and work at it," says Jacobs, also a spokesperson on caregiving for the American Heart Association and author of *The Emotional Survival Guide for Caregivers* (2006, Guilford Press). "Step back and admit to yourself that the relationship is not going to be what it was. But what can it be? If it's not going to have the gratifications of the

past, are there gratifications that can still be derived from the relationship as it is or might develop over time?"

When caregivers or family members can't accept change, they can develop feelings of resentment toward their loved one and frustration over their circumstance. Worse yet, they may emotionally withdraw from the relationship altogether, Jacobs says. But other times, life-threatening events like a heart attack can push people in the opposite direction, reminding them to focus on the small pleasures of life like enjoying the smell of fresh brewed coffee in the morning.

While it's important to be realistic, Jacobs says caregivers need to take notice of what they may have gained through the process. He says many people are too focused on their future dreams like buying that new vacation home. "As embittering as it sounds to lose those dreams, it forces people to really focus on what they get [out of] every day," he says.

Some family members or caregivers may need to broaden their search outside the relationship to have specific needs met. For example, he says if adult children were receiving guidance from a parent who is no longer able to provide it, they may be able to find another parent figure in their life—perhaps an aunt or uncle—who can step in and play the role their parent once played.

While active hobbies like jogging or rock climbing with your loved one may be out of the question, now is the time to get creative, identifying sedentary activities you can enjoy with each other and that are meaningful. This is a very conscious process, he says, adding that this is not the time to settle.

Likewise, as caregivers, be aware of the messages you tell yourself. When people say, "I'm trapped," for instance, that's a "life-sucking" message, Jacobs says. Instead, change the message to, "What can I do that's really significant and derive small pleasures from?"

Relationships generally don't require a lot of hoopla to be meaningful. What makes them worthwhile, he says, are moments of comfort and mutual, positive respect for each other.

"This isn't rocket science," Jacobs says. "People have to figure out ways to set aside their big dreams and learn to find pleasure and meaning in what they have. It's the small moments that add up to happiness. That should be what [you're] aiming for" ■