

Caring for the Caregiver

The well-being of caregivers is often overlooked, but their lives can be improved with a strong support group and a lot of laughter.

By Mark T. Haggard



It's 2 o'clock on a late December morning and I'm watching the television in an emergency room. In the bed in front of me, my wife rests comfortably for the first time in a week of her renewed struggles with ankylosing spondylitis. But, I am still gut-wrenched: "Will my wife will be all right?" I asked myself. "When will the next episode requiring a trip to the ER occur?" "How much will this

visit cost?" "Will I need to take time off from work next week?" "How many sick days do I have left?" "How will I finish my Christmas shopping?"

Every time I take one of my family members to the doctor, these same kinds of questions run through my mind. Individuals who live with chronic illnesses understand the financial, emotional and psychological impact of immune difficulties. But,

what's often not understood is the impact these illnesses have on caretakers.

Caregiving and the Immune System

According to research conducted by Dr. Ronald Glaser, professor of molecular virology, immunology and medical genetics at the Ohio State University Medical School, and Janice Kiecolt-Glaser, professor of psychology and psychiatry, caregiving actually has a negative impact on the immune system.

The Glasers' research team noted changes that amounted to a shortened life span of four to eight years due to changes in the caregiver's body at the molecular level. Telomeres are genetic material protecting the end of each chromosome, like the cap on the end of a rope. As cells divide, an enzyme (called telomerase) works to repair the damage to those chromosomes. "Think of it as a frayed rope," the Glasers say. "If the caps weren't there, the rope would unravel." As we age, the telomeres shorten and the activity of the telomerase enzyme lessens. Caregivers of the chronically ill, according to the study results, have a pronounced decrease in telomeres and the production of telomerase.

Further tests conducted during the

study compared a control group of non-caregivers to caregivers, which showed levels of stress in caregivers to be twice that of the control group. Caregivers also had fewer lymphocytes, an important component of the immune system, and higher levels of cytokines.

Life as a Caregiver

Eighteen-year-old Cathryn Achilles of Wheatland, Calif., recently graduated from high school; she had been home-schooled by her mother, Deanna. Cathryn lives with ataxia telangiectasia (AT) and Deanna says that, because AT compromises the patient's muscle control, taking care of her is a 24-hour-a-day job. "Every time I think I can leave, I end up regretting it," Deanna states. At times, while her daughter was sleeping, Deanna would leave for only a few minutes and return to find that Cathryn had fallen and injured herself.

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It's also tough on Cathryn's siblings. "The older they get, the more I find out how hard it's been," Deanna says. Older sister Crystal, a fiery independent type who shared a room with Cathryn, complains that "Cathryn gets catered to." While growing up, younger brother Robert had to give



up much of the limelight to his sister.

Deanna says that she is in complete control of the care-giving situation, and it is only when something out of the ordinary occurs that she feels out of sorts. During a recent trip to a Bay Area hospital, Deanna broke down from the stress. After first refusing to admit her daughter, the doctors demanded X-rays that would have contributed to the deterioration of Cathryn's already compromised body. Because of continual miscommunications with the doctors at the hospital, she put herself on a "24-hour watch" at Cathryn's bedside. Deanna "lost it" on the third day when a nurse started an IV medication in Cathryn's line that was prescribed for the child in the next bed.

Coping as a Caregiver

Maya Hennessey is a "family caregiver specialist" in Chicago, and author of *If Only I'd Had This Caregiving Book*. She is the Midwest coordinator for the National Family Caregivers

Association, an organization that is committed to providing services to caregivers at no cost. Hennessey has devoted the last 30 years to collaborating with treatment providers to improve caregiving for families. She has found that caregiving creates demands — physically, emotionally and spiritually. Normally, the body has a chance to recover from those demands once an episode has passed, but when these demands are constant, as in the case of a long-term illness, the body does not have the opportunity to recover, and the immune system is weakened.

For help, Hennessey recommends a strong network of support, looking within your own group of friends and neighbors. "You have to look within your own circle and see who is available and willing to help," she explains. "Sometimes it won't be immediate family." Deanna has found support in the emails and Facebook pages of her cyberfriends who have family members with AT. "No one else can understand

the uniqueness,” Hennessey adds.

When asked how we are doing, we caregivers often answer, “Fine.” Perhaps that is for the protection of those whom we run into. One day while shopping, Hennessey ran into a friend who asked how things were going, and she responded with a 30-minute explanation. A few days later, the two spied each other on opposite sides of the store; Hennessey started walking toward him and he turned heel and ran to the exit. Talking to another friend the next day, Hennessey thought that he might still be running!

Rather than give the standard answer of “fine,” Hennessey advises

we delegate, the pressure does mount on caregivers and we begin to burn out. Hennessey says that we need to find things in our own lives — maybe things we’ve given up on — that have always been healing and comforting. Deanna admits: “I check out a lot. I look at my friends’ Facebook pages. I like to read the classics; they are a great escape.” She also says that her faith keeps her grounded: “I’m most stressed when I’m out of my [Christian] walk.”

For Hennessey, “Going out with my girlfriends and laughing was important, but when my husband got sick, life was not so funny. I was out at a function and a friend intro-

were punctuated by bouts of uproarious laughter. Dr. Bill Cosby once noted, “If you can laugh at it, you can get through it.”

I subscribe to the adage: “Those who refresh others will be refreshed themselves.” Refreshing others has helped me cope with my own family’s immune issues; it is an opportunity for me to help people laugh, relating the humorous side of what our kids do despite their afflictions. We need to laugh. We need to make others in our situation laugh. We have to be the support system that someone else somewhere needs. We need to give life back to those who are having life stolen from them.

That night in late December, in the midst of my long list of life questions, my wife turned toward me and produced a Dilaudid-induced smile. The turn put my mind at ease and I leaned closer to her, returned her smile and asked, “Can I have some?” I could almost feel my financial, emotional and psychological worries being washed away in a rush of serotonin. That night, a few more months were added to my life. ■

Rather than give the standard answer of “fine,” Hennessey advises caregivers to have a short list of things that others could do to help take the pressure off them.

caregivers to have a short list of things that others could do to help take the pressure off them. People are not going to know what you need if you don’t tell them. And, if you ask, you will find that people are willing to help with errands, mowing the lawn, making phone calls or preparing a meal. “You have to begin constructing your life around delegating and asking for help,” Hennessey says.

Nevertheless, no matter how much

duced me to two other caregivers and we started sharing experiences and laughing and finding humor in our situations. That night, I slept like a baby.”

Laughter Is Medicine

Laughter is great medicine. Laughing releases endorphins that make us feel better and also increases levels of serotonin, a hormone that counters depression. My interviews with Hennessey and Deanna for this article

Sources

- National Family Caregivers Association: www.thefamilycaregiver.org, (800) 896-3650
- If Only I’d Had This Caregiving Book: www.mayahennessey.com/maya_book.php, (800) 280-7715



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