

Caregivers Need Care, Too



Christopher News Notes

CAREGIVING IS HARD WORK. AND LOTS OF US ARE DOING IT.

Recent statistics show that 66 million Americans are caring for a parent, spouse, child, family member, or friend.

And with the burgeoning growth of people over age 65 (10,000 people a day are crossing that threshold), studies predict that nearly every middle-aged person will be caregiving for someone in the next 20 years.

Most of the attention is directed to the individual who needs our care.

We take them to doctor appointments, help them with

housework, make sure they are eating properly, help them navigate the confusing and oftentimes fragmented health care system. It takes time, energy and, yes, creative maneuvering to schedule caregiving into our already busy lives. Moreover, there is not a clear, charted course for caregivers to follow, since this is a job for which few of us have had any prior training.

There is another side of caregiving, however, that often gets overlooked: caring for the caregiver. Caring for ourselves.

It might seem selfish to complain about the situation when we really are so much better off than the person who needs our assistance. Feelings of guilt may crop up when we let ourselves dwell in thoughts that our own lives might be suffering. It's easy to think we should be able to "do it all"—be a helpmate to our spouse or parent; take care of the kids; hold down our jobs; and have time left over, from the medical appointments and daily tasks, to give our loved one the emotional support they truly want.

So where does that leave us? It often leaves us exhausted, searching the Internet for answers, lonely and anxious, not knowing where to turn for help—because we aren't the ones who need help. Or are we?

The truth is that caring for someone we love is not only a one-way relationship. Each side needs replenishment at times. We must remember to try to maintain our own health, happiness and important relationships while caring for a frail loved one. But how do we do that?

In her Christopher Award-winning book "The Gift of Caring: Saving Our Parents from the Perils of Modern Healthcare," geriatrician and public health advocate Elizabeth Eckstrom, MD, MPH, writes that she has seen hundreds of family caregivers suffer in this role that they take on because they love someone, despite having a plate that is already full. And in the midst of it, they discover how difficult it is to find support and relief.

Recognizing these challenges, Dr. Eckstrom pres-

Take Time to Reflect

Marcy Houle, co-author with Dr. Eckstrom of "The Gift of Caring," was a caregiver for both her parents for a total of 14 years. During this time, she kept journals, which helped give her perspective of all her family was going through, and later formed the basis of her book. Through her writing, she found the importance of thinking of caregiving, not as a job, but as a journey.

"Through the crises that sometimes arose, we were given the chance to see life as it was in real time, not by the green-screen backdrops of fantasy. Along the way, my mother and father were showing all of us what it meant to endure problems and suffering with grace. For all of us, it was a trip of endurance through mountains and valleys...a test of grit and faithfulness. This was our family's journey—with each other and for each other."

ents several steps geriatricians have found that can provide the restoration caregivers sorely need. Becoming armed with these strategies helps ensure success in our own caregiving journeys.

Develop a Self-Care Plan

Put in writing goals for self-care activities, reflecting on those things that rejuvenate us. What provides us joy and refreshment? Is it exercise, gardening, spending time with friends, church, playing piano?

Cindy from Oregon knew she had years ahead of her as a caregiver when her young daughter was diagnosed with a serious form of juvenile rheumatoid arthritis. A sense of overwhelming worry nearly consumed her. From the recommendation of her doctor, Cindy learned about the importance of developing a care plan for herself. While deliberating what things brought her pleasure, one activity stood above all else: running. In her care plan, Cindy kept a date book to ensure that she made time to run. When she could, she signed up for races. Running improved Cindy's moods and helped keep other parts of her life in balance.

As life can get hectic, Dr. Eckstrom advises that we pay attention when we haven't done any self-care for a few days. It is important then to stop and think about what needs to change to get back to our plans.

Find Your Team

Who are the people in our lives who keep us in

balance? Who is honest enough to tell us when they see us at our wit's end? Who is willing to talk to us at any time, even midnight, when we are exhausted from another crisis? These individuals are our "team." They can be a sister, a spouse, a close friend, a clergy person, a counselor. The most important thing is that they will be there for us, and that we are willing to tell them what is happening in our life. Not sharing will lead to more difficulties down the road because it will become harder to confess when we need a break.

First, Be a Family Member

Catherine from Massachusetts learned this the hard way. She was doing everything for her mother who lived with her—taking her to doctors' appointments, getting medical supplies, helping her with daily functioning—which was getting to be increasingly more difficult as her mother's needs continued to rise. At the same time, Catherine found herself ignoring her own needs. With all the effort she expended on her mother, there was little left over for her to give to the rest of her family. Moreover, Catherine had little energy for what her mother really wanted: a loving relationship with her daughter.

It is not only acceptable but essential that we try to find respite help when we are caregivers. It's important to tend to our loved one's daily needs, but it is more crucial that we be able to enjoy our time spent together. A family member's physical

needs can be met by another caregiver, but no one else can provide the emotional support and love that we can; this is a treasure to be protected and fostered.

Maintain Your Own Health

It's easy to neglect ourselves when our focus is entirely on someone else. When that happens, we can find ourselves depressed, having trouble sleeping, and fatigued. We can develop symptoms, such as bodily aches and pains and abdominal problems.

Sarah, who helped care for her father as he suffered from mild cognitive disorder, began having headaches. At first she disregarded them, but over time, they became more regular. As her father's health continued to decline, Sarah's headaches became worse. Then, she also began having digestive ailments.

Worrying that she might be developing a brain tumor, Sarah at last made an appointment with her own doctor, who was aware of her situation and correctly diagnosed her problem. Sarah did not have a brain tumor; rather, her symptoms were signals that she was under great strain, and her body was taking the brunt. This happens frequently, and caregivers need to be cognizant of signals that our own health might be at risk. A good strategy is to ask a family member or close friend to be observant of us, looking for warning indicators that we may need help. And we should also be sure to see our own doctor regularly.



"It's better to light one candle than to curse the darkness."

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Editor-in-Chief: Tony Rossi

The Christophers

5 Hanover Square, New York, NY 10004
212-759-4050 • 888-298-4050

mail@christophers.org • www.christophers.org

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Look for Outside Help

Caregiving needs rarely go down. For that reason, it's helpful to take proactive steps early to research other ways to find aid. Geriatricians suggest that we talk to our loved one's health care providers about what community services might be available for them, and for ourselves as well. For example, if our parent qualifies for Medicaid, he or she may be able to get some free in-home or short-term respite care. For those caring for older persons, local senior centers often can direct us in locating support. The Alzheimer's Association and state-sponsored Area Agency on Aging offer resources that may help us with our caregiving needs. And we should be aware that if an older person is in a facility and things are not going well, the long-term care ombudsman can step in.

Turn to Faith and Community

Studies show that feeling a connection with something bigger than ourselves in times of great need—a loving God who is guiding and supporting us—can bring courage and solace. Faith, in other words, can be a light in the darkness. And many faith communities provide assistance of different kinds that often don't come from other public resources. Some have networks of drivers to assist those who no longer drive. Others help provide meals. Still others offer relief assistance with getting family members to appointments.

Caregiving is a hard job, but it is also a "heart" job. And eventually, as difficult as it is to accept this truth, there will come a time when our caregiving role is through. At this time, the words of writer Tim Douglas Jensen can shine meaning on all we have done: "The real comfort comes in knowing that we've cared, that we've invested ourselves, and most of all, that we have loved."

"Caregiving often calls us to lean into love we didn't know possible."

—Tia Walker, from *"The Inspired Caregiver"*