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The job of caring for ailing loved ones is often daunting. Now, many are asking...

How Can We Help Our Nation's Caregivers?

By Gail Sheehy
Published: September 9, 2007

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"It's cancer."

Those words from my husband's oncologist plunged us into the whirlpool of fear, denial and confusion that suddenly drafts many in middle life into the wars against aging and physical decline. Within the first few days of sharing the news with stunned family members, Googling disease sites, tracking down doctors, comparing hospitals and growing dizzy from conflicting opinions, it began to

dawn on me that my life had changed radically. I had a new role: "family caregiver." It's a job nobody applies for. You don't expect it. You won't be prepared.

When I assumed that role, I became part of an unpaid army of 44.5 million Americans who take care of adults. (An additional 6 million provide care to children under 18 with mental or developmental disabilities.) Today's typical caregiver in the U.S. is a 46-year-old woman who holds down a paid job and spends 20 hours a week providing care for a sick or disabled parent, grandparent, spouse or child. The numbers will only grow.

My transition to caregiver began, as it does for many, when it came time for my husband to leave the hospital. A discharge planner may hand you a list of facilities that you have only a day or two to investigate. You learn that Medicare will decree whether or not a patient qualifies for "acute rehab," the type necessary to restore functionality.

A doctor tipped me off that the patient's fate often is determined by the number of steps he or she can take. Less than 12 steps, and the patient is consigned to "long-term care" in a nursing home, where little attention is paid to the possibility of ever becoming independent again. I will never forget sneaking into my husband's hospital room at dawn on the day he was to be evaluated. He looked so weak and tired, with an elephantine trunk of oxygen and coils of IV tubing sprouting from his body. I had been working with him at the bedside to build strength. We had gotten as far as six steps.

"Boomers are shocked when they find out Medicare won't pay for any long-term care for chronic illness," says Gail Gibson Hunt, CEO and president of the National Alliance for Caregiving. At most, Medicare may provide a skilled home health aide for a few hours a day for a limited period of time.

Medicaid—intended as a safety net for specific low-income populations, including the disabled and children—will only reimburse people who have depleted their assets. In 2006, in an attempt to stanch the huge costs of health care, Congress made it harder to qualify for Medicaid's long-term care benefit by factoring in the value of one's home. "Our system is set up to encourage families to take on the full responsibility for long-term care and to discourage them from resorting to Medicaid," notes Carol Levine, editor of the book *Always on Call: When Illness Turns Families into Caregivers*. "Only when you are totally desperate and have exhausted every resource will the government step in and help."

Many caregivers are women and men in their mid-40s who are still building careers, investing for retirement and anticipating the freedom of an empty nest. Once they take over the caregiver role, they often experience sharp drops in

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income as a result of huge losses in wages and personal savings.

The killer statistic is this: Over the course of a lifetime, caregivers sacrifice an average of more than \$500,000 in total income.

After my husband left the hospital, I hired a professional nurse to do the medical procedures at home, at \$35 an hour. How many people can afford to hire paid caregivers?

A perfect storm is brewing. As boomers spend down funds on elder care that were earmarked for their own retirement, they are asking themselves: "Who will care for us?"

Action at the federal level has been minimal. Last year, Congress did pass the Lifespan Respite Care Act—which provides grants to states to develop local respite-care programs for caregivers desperate for a few hours' break—but so far it has failed to appropriate any money. Meanwhile, some states and private companies are looking for solutions. Among them:

- California has created comprehensive paid family-leave insurance—the first such program in the nation. Most employees in the state can take up to six weeks' leave to care for a seriously ill family member and receive 55% of wages. (In contrast, the federal Family Leave Act lets employees take time off without fear of losing their jobs—but without pay.)
- More states are looking for new ways to provide support. Between 2004 and 2006, dozens of states introduced a total of 78 caregiving bills—but only 16 survived the legislative process. The most popular proposals involved tax incentives for caregivers. This year, 12 states have been considering bills to expand family and medical-leave benefits.
- Portland, Ore., has pioneered the first education program for family members who are caring for older adults who have stroke, Alzheimer's, Parkinson's disease or similar long-term conditions. Called Powerful Tools for Caregivers, the six-week class teaches caregivers how to be effective in using community resources and managing their stress.

The Portland program—which has been replicated in more than 20 states through collaborations with community-based organizations like AARP chapters and Area Agencies on Aging—has reached 15,000 family caregivers. No one is allowed to make a financial profit from this service.

- Private companies have developed caregiver-friendly policies. Nike and Intel, for example, have adapted the Portland, Ore., course for their caregiving employees. EverCare sells employees the services of a "care manager" to walk their caregiving employees through the maze of options. Johnson & Johnson has created an online community that offers an array of resources for dealing with the bureaucracy and stress that caregivers face.

These are signs of progress. As baby boomers age, however, so much more needs to be done. We must design the system we want to grow old in.

Gail Sheehy is collecting stories from family caregivers for her next book. If you would like to share your story, please [click here](#).

For more information about the Powerful Tools for Caregivers program, please contact powerfultools@aol.com.

Access the latest resources, connect with others and find support by becoming a part of the [National Family Caregiver's Association \(NFCA\)](#).

For advice on how you can cope physically and psychologically as a caregiver, read "[What Caregivers Need to Know](#)"

For additional information and resources on caregiving, visit:

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It's all about personal responsibility

By ChrisG on 9/11/2007 4:41:PM

Ms. Sheehy was right on about the cost and effort required by the sandwich generation in caring for our parents and children. However, she was completely off base in her desire to have the government (otherwise known as the taxpayer) to provide the resources to caregivers in order to protect their savings and assets. It is the responsibility of each of us to purchase long-term care insurance policies when we are young and healthy and stop believing that somehow it is the responsibility of others to take care of us. I am an advisor to my clients about long-term care insurance and the possible results of not taking it upon ourselves to protect our retirement assets. Many times it falls on deaf ears because they believe it can't happen to them or the government will take care of the costs. Stop asking our politicians to burden us even more when the solution is available to us out of our own individual pockets instead of others.

Caring for my mother for 9 1/2 years with Alzheimers

By stargazersunshine on 9/11/2007 3:13:PM

I can say the most important thing i have learned from the beginning to now is who your "Real Friends" and "family" are. Dealing with taking care of my mother, moving her into our home (I have no children) but my husband is also 64 years old with medical issues and I am 48 years old it is difficult. i had to give up my career at a City Job and knew when mom was diagonised that I would Always take care of her till the end, I now have my own Private Investigative Firm working and setting my own hours taking care of mommy. It has been hard cause in the beginning I never thought she would ever be a stage 3-4-5 i wa in denial well she is now stage 5 the ending phase, it is hard we need more government support, funding and resources to deal with Alzheimers Disease I try and get everone I know involved with it,

Caring for the Caregiver

By debra schulz on 9/11/2007 12:33:PM

I took the class offered in Portland last year. It was very helpful. I am my mother's caregiver...full time now. I had to quit my job of 27 years to take this on. I am honored to be able to do this...and it is exhausting. Many times I feel swallowed up with her Alzheimer's Disease. It affects every aspect of my life. I'm thankful to family and friends for their prayers and support...and yet I often feel like I am struggling with this alone. She is constantly deteriorating, physically and mentally. It's a hard thing for both of us to deal with. God bless all those giving care with patience and compassion. God bless all those recieving care. If you know someone in this boat...support them. Be patient with them...STAY CONNECTED WITH THEM. (Even if you're uncomfortable with their situation. Let them know they are not alone.)

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