

Caring for Those with Brain Disorders

By Denise Myshko

Caring for patients with Alzheimer's, ALS, and other neurodegenerative diseases can be challenging. Experts take a look at the challenges and how pharma companies, advocacy groups, and other stakeholders in the care continuum can help improve the quality of life for patients.

Many of us will be caregivers at some point in our lives. Age, debilitating disease, and chronic health conditions mean many of us will take on the role of caring for relatives.

An estimated 43.5 million adults in the United States have provided unpaid care to an adult or a child in the prior 12 months, according to a study released last year by National Alliance for Caregiving and AARP. About 34.2 million Americans have provided unpaid care to an adult age 50 or older.

About a quarter of those surveyed say they have been in the caregiving role for five years or more. On average, caregivers spend 24.4 hours a week providing care, and only half of the caregivers say they receive help from other unpaid caregivers.

Industry leaders say it's important to understand the individual behind the disease. Patients with central nervous system disorders have different challenges and needs depending on the disease, says Peter Anastasiou, U.S. president of Lundbeck.

"We pride ourselves on seeing the person behind the disease," he says. "Patients don't

want to be defined by their disease. They want to be as normal as possible, and each of those diseases has different challenges. We want to help people overcome those challenges."

Patients with Neurodegenerative Diseases

About 26% of caregivers surveyed by the National Alliance for Caregiving and AARP say they are caring for people with memory conditions such as Alzheimer's. Nearly one in 10 says he or she is providing care for someone who is 75 years of age or older.

Caring for someone with Alzheimer's disease, other dementias, or other brain-impairing disorders can be more stressful than caring for someone with a physical impairment. Caring for someone with a cognitive disorder can be a 24/7 job due to the unpredictability of the patient's behavior.

It can be overwhelming to think about caring for a person who has even moderate memory loss, says Terry Fulmer, president of John A Hartford Foundation, a private, nonpartisan philanthropy dedicated to improving the care of older adults.

"Caregivers, family members, or friends have a sense of profound loss that the person they love is not there anymore even if they're sitting in front of you," she says. "The interconnectedness of lives and all those affected can become very, very complex and very disheartening. It can also be a profound and humbling experience to observe caregivers who are giving their all and doing it with devotion and love."

Ms. Fulmer adds that caring for patients with Alzheimer's or ALS can be expensive.



We have come a long way toward earlier and better diagnosis of Alzheimer's and having symptomatic treatments for patients. But there are still tremendous challenges, not just in medical treatment but in support for caregivers.

DR. GARY SMALL
UCLA

“We know that more than 15% of people over the age of 70 have some form of cognitive impairment or dementia, and that in 2010, the economic cost was more than \$100 billion for care and another \$150 billion to \$200 billion for the monetary value of informal care,” she says. “Caregivers often have to leave the workforce or hire someone, and all those costs come into play.”

Medicare, Ms. Fulmer says, paid about \$11 billion in dementia-related costs in 2010.

“The average per-person cost of dementia ranges between \$40,000 and \$60,000 a year depending on the cost of informal care,” she says. “We know Medicare is doing a lot to help. We know that the Affordable Care Act and accountable care organizations will be working even more closely with people who are eligible for Medicare and eligible perhaps for Medicaid, to see how they can provide continuity of care and give them the most appropriate care in the least restrictive environment.”

Ms. Fulmer says the challenges of caring for such patients will only grow as the number of older Americans increase and now is the time to get ready.

“There will be about 88 million people over the age of 65 by the year 2050,” she says. “While that seems a long way off, we have to prepare now and start thinking about how to maintain our momentum toward providing care; long-term services and support are going to be essential.”

Gary Small, M.D., director, Psychiatry Division and professor, psychiatry and biobehavioral sciences, at UCLA, says the wave of baby boomers who are reaching the age of risk for Alzheimer’s and other neurodegenerative diseases will create a huge influx of dependent people.

“We don’t have any cures for Alzheimer’s disease, but we do have symptomatic treatments for patients in the moderate-to-severe stages of the disease,” he says. “There have been advances in the field of drug development. When I started out, we didn’t have any medicines to treat Alzheimer’s. We have come a long way toward earlier and better diagnosis and having symptomatic treatments for patients. But there are still tremendous challenges, not just in medical treatment but in support for caregivers.”

“Caregiving is a burden that isolates,” Dr. Small continues. “And it mostly falls on women. Furthermore, we know from extensive research that caregivers are at high risk for depression.”

Caring for those with chronic or long-term conditions seem to make the caregiver particularly susceptible to emotional stress, as about one out of every two caregivers of someone with a mental health issue (53%), Alzheimer’s or dementia (50%), or a long-term physi-



We don’t think our responsibility is only to offer a pill. Helping patients have knowledge about where to access other services that they need is also important.

PETER ANASTASIOU
Lundbeck

cal condition (45%) report feeling emotional stress, according to the National Alliance for Caregiving and AARP survey.

Caring for a close relative, such as a spouse or parent (45% and 44%, respectively), can be even more emotionally stressful for caregivers.

Dr. Small says caregivers are so busy, they don’t have the time to get outside help.

“There are caregiver support groups throughout the country,” he says. “The Alzheimer’s Association, and other organizations sponsor these activities but the average caregiver is so busy dealing with her job and family that she doesn’t have time to take care of herself. Caregivers are overwhelmed and don’t get the help that they need.”

Just 32% say they have paid help from aides, housekeepers, or other helpers. One in three caregivers have no help at all, according to the National Alliance for Caregiving and AARP.

Role of Pharma

What patients and caregivers need the most is support, says Peter Rooney, General Manager, Ogilvy CommonHealth NANO.

“Pharmaceutical companies can play a big

About Today’s Caregivers

- ▶ 82% of people care for one person who is likely either living with the caregiver or living within 20 minutes of the caregiver.
- ▶ 60% of caregivers are female. The typical caregiver is a 49-year-old female caring for a 69-year-old female relative, most likely her mother.
- ▶ 38% of caregivers report high emotional stress from the demands of caregiving.
- ▶ 34% of caregivers have a full-time job, while 25% work part time. Caregivers who work do so for 34.7 hours per week on average.
- ▶ 32% of caregivers provide at least 21 hours of care a week, on average providing 62.2 hours of care weekly.
- ▶ Caregivers have been caring for four years on average, spending 24.4 hours per week helping with activities such as bathing, dressing, housework, and managing finances.



Source: National Alliance for Caregiving and AARP

role in education, customizing resources, and providing education for patients,” he says. “There is a wide range of ages when evaluating the spectrum of neurodegenerative disease. Caregivers oftentimes are the sandwich generation; they have children of their own and are also caring for their parents. Pharma companies can help provide assistance for patients and caregivers.”

Mr. Rooney says one of the most important things is making connections for patients and caregivers with other patients and caregivers.

“We’ve found there is tremendous power in a caregiver knowing that she is not alone,” he says. “If pharma companies can help in some way to connect these people, there’s a lot of power in that.”

Lundbeck, for example, works with advocacy groups to try to understand the needs of patients in different disease states.

“For example, we realize that for people who have rare disorders such as Huntington’s disease or Lennox-Gastaut syndrome, which is a rare form of epilepsy, their caregivers want to meet other people who are going through



Pharmaceutical companies should think about putting some of their corporate philanthropy toward family caregiving.

TERRY FULMER
John A Hartford Foundation

the same challenges and share best practices,” Mr. Anastasiou says. “We fund scholarships for patients to be able to connect with other families by attending conferences and meetings, who couldn’t otherwise attend for financial reasons.”

Executives at Lundbeck stress they work to understand the needs of patients and caregivers so they can deliver customized approaches.

“Patients and caregivers are going through a great deal of burden with these diseases and we don’t think our responsibility is only to offer a pill,” Mr. Anastasiou says. “A pill is only one part of the solution, which is often multi-factorial. Helping patients have knowledge about where to access other services that they need and making sure that they have access to medications are some of the things that we’re doing.”

Lundbeck’s goal is to support those living with brain disorders in a variety of ways that extend beyond therapeutics. One example is the company’s work with the Epilepsy Foundation to create a program called Studio E:

The Epilepsy Art Therapy Program.

This program is for people with various types of epilepsy and who are at different stages of their epilepsy journey. The program offers a unique way for people with epilepsy to socialize with others and open up honestly about daily challenges in a trusting, expressive environment.

Lundbeck is developing initiatives in the



We’ve found there is tremendous power in patients knowing that they are not alone. If pharma can help in some way to connect caregivers, there’s a lot of power in that.

PETER ROONEY
Ogilvy CommonHealth
Medical Marketing


Alzheimer’s space, which aims to offer a meaningful spectrum of support. Company executives are involved with the patient community in a variety of ways, and the company has gained insights that are helping researchers better understand the factors that impede timely diagnosis and treatment.

The company has applied insights into active support. For example, Lundbeck found that one key objective is helping people with Alzheimer’s preserve their sense of self for as long as possible, knowing how challenging this becomes as an individual’s disease progresses.

The company supported an exhibit curated by a Chicago art museum that features an artist’s self-portraits throughout the progression of his Alzheimer’s disease. As part of this support, Lundbeck was part of a panel conversation that included the artist’s family.

Additionally, through Lundbeck’s support of a program called Right Direction that is led by an advocacy group and employer coalition, employers have access to free resources for addressing depression and its impact on productivity in the workplace. Right Direction gives employers tools to share internally, including educational presentations such as the “Field Guide,” which is a toolkit that includes a step-by-step implementation plan and corresponding promotional resources.

Lundbeck also supports Connect 4 Mental Health, a nationwide initiative that offers innovation awards to community-based organizations.

This program aims to encourage collaboration among the mental health community and other community-based organizations — such as emergency services, law enforcement, and public housing — to develop localized interventions that provide additional support for those with serious mental illness and also may help address larger community problems. 

Costs of Caring for Those with Alzheimer’s Disease

A study of 1,715 caregivers of noninstitutionalized Alzheimer’s patients shows that direct and indirect costs of Alzheimer’s disease are considerably lower for patients with fewer symptoms.

The direct costs of caring for Alzheimer’s disease patients for six months totaled \$3,129, whereas the indirect costs were \$26,080.

Patients with more-frequent symptoms used all healthcare resources — including the hospital, emergency room, physicians’ services — more often than those with less-frequent symptoms. Those with lower levels of physical and instrumental functioning also used the hospital and physicians’ services more often than those with higher levels of physical and instrumental functioning.

Caregivers of these more severely impaired patients spent more hours providing care and reported missing more work than those caring for higher-functioning patients. Patients with more advanced stages of the illness require constant supervision and help with the most basic life functions. This systematic and progressive decline has wide-ranging implications for healthcare costs.

Source: Dr. Gary Small, UCLA

Healthcare Businesswomen's Association

Woman of the Year event

May 12, 2016 | New York Hilton Midtown

Join us. Early registration rates end April 5, 2016



Honoring

Woman of the Year

Jennifer Cook

head of region Europe for
Roche Pharmaceuticals

Honorable Mentor

Jacopo Leonardi

executive vice president and
president of the immunology
division at Baxalta

STAR

Deborah Coogan Seltzer

director of enhanced search,
North America at
Spencer Stuart

(c) PharmaLinx LLC. Rights do not include promotional use.
For distribution or printing rights, contact mw@pharmavoices.com



Review sponsorship opportunities
www.hbanet.org/sponsorship

www.hbanet.org/WOTY