Activists unite at Long-Term Care Caucus

The United States is undergoing a radical demographic shift that will change the face of the nation. By the 2030s there will be more than 72 million Americans over the age of 65—twice the number there is today.

As the baby boom generation and even Generation X begin to age, we all need to think about long-term care in the future. The National MS Society has begun to explore new ways to champion the needs of people with MS. We don’t know what all of the solutions will be yet, but we’re beginning to test some of them now. The Society believes people can receive the care they need without sacrificing dignity, autonomy, or the opportunity to grow.

“Then he carried my groceries up the stairs for me,” I overheard an elderly woman with disabilities say to a friend on the cross-town bus a few days ago. “I was so touched, I cried.” Someone helping her carry her groceries obviously meant the world to her, making her life that much easier.

From a little help with everyday chores to skilled nursing home care, long-term care support takes many shapes. Today there are options for how to live the rest of your life should you need assistance. As part of a bold new initiative, the National MS Society is now planning to provide care management and financial assistance for people with MS, and many who will benefit from this support will have long-term care needs.

Putting our heads together

Last November, activists met at the Society’s first Long-Term Care Caucus in Santa Monica, California. “Staff from all around the country attended to pool knowledge and experiences, and share successes, failures, and nuts-and-bolts advice,” said Dorothy Northrop, the Society’s senior director of Clinical Programs.

Leon LeBuffe, president of the Southern California Chapter, which hosted the caucus, elaborated: “We looked at needs assessments and questionnaires from people with MS, bud-
gets, plans, timelines, project proposals—you name it—with an eye on how to get enough funding to become a real resource for people with long-term care needs.”

Pat Knoerle-Jordan, president of the Gateway Area Chapter in St. Louis, Missouri, described how her chapter sent out the kind of request for proposals that is usually sent to scientific researchers. These went to carefully selected nursing homes. “Our goal was to get a wing dedicated to people with MS in at least one of these facilities. We wanted to make it happen. We didn’t want to wait for it someday. So we pushed for it to happen,” she said. Now the Gateway Area Chapter is showing others exactly how their initiative worked.

A spectrum of service
For many people, “long-term care” instantly conjures up images of life in a nursing home. That is one option. But as Gateway is showing, nursing homes geared for adults with MS break many stereotypes. Moreover, a nursing home is just one choice, Northrop said. Programs include chore services, personal assistance, meals on wheels, home visitors, caregiver support, transportation, adult day programs, assisted living, and accessible housing.

Activities of daily living are not limited to cooking, cleaning, and bathing, LeBuffe stressed. Daily living includes “going bowling, yoga classes, going to a ballgame, playing cards, going to parties and concerts, attending book clubs, doing word games, or just sitting talking and having time with friends,” he said. “Many adult day wellness programs help people get back into the community. People work on their physical wellness and their cognitive wellness and just have some fun.”
**A unique population**

“People with MS have unique needs, and it’s critical that we help long-term care providers develop more sensitivity to this,” Northrop said. People with MS in nursing homes are usually younger and more alert than frail elderly residents. In a study conducted in 2002 by researchers at Texas A&M University, the median age of residents with MS was 57.5 years, while the median age of all other residents was 76 years.

“Long-term care simply cannot mean sitting in a room with elderly people feeling like one’s life is over,” Northrop said. In order to serve younger, more energetic people, providers need more staff, more investment. “It’s expensive,” she said, “and providers need a sense of mission—they need to be interested and committed.”

Knoerle-Jordan explained that it took her chapter years of planning and groundwork to develop both the model and the collaboration needed to create the dedicated MS wing at the nursing home the Gateway Area Chapter eventually selected.
“We wanted a social model, not just a medical model,” she said.

In Kansas, the Mid America Chapter gave itself the goal of providing accessible, affordable housing for all people with MS. To do it, the chapter teamed up with the non-profit Accessible Space, Inc., and successfully applied for grants from the Department of Housing and Urban Development. Two new housing complexes, the Mid America Commons and the Melissa Anne Hanger Apartments, had grand openings last October.

“Chapters like Mid America and Gateway Area are taking the lead,” Northrop said. “They are showing Society staff and volunteers how to make it work.”

At the Commons, little things count: a stove top designed to prevent burns, extra-large cabinet handles—and friends. Patricia Roy, shown above with Maltbia-Smith along with her dog Yasmin in the common room, says she is enabled by her low sink.

Collaborating for success
Activists at the caucus pledged to work with other area organizations, donors, and people with MS to create sustainable long-term care programs where life goes on.

“Staff and volunteers can reach out to other people and organizations,” LeBuffe added, pointing out that churches often sponsor their own “friendly visitor” programs. Knoerle-Jordan said that the success of her chapter’s program is “dependent on our relationship with people with MS and what they tell us about what they need.”

“It’s a challenging goal—to ensure that every person with MS who needs quality, age-appropriate long-term assistance can get it—but we’re gearing up to meet it,” Northrop concluded.

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