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CARE EXPERTS EXPLORE LTC FUTURE

Second of two articles

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Should boomers quit their jobs when called on to care for their ailing parents? What can be done to encourage families to seek hospice and palliative care early enough for elders to benefit the most? How can professionals in aging help families culturally sensitive to the stigma of mental illness deal more forthrightly with signs of dementia in their elders? What are the keys to creating an effective long-term care (LTC) support system for family caregivers?

These are some of the wide-ranging concerns about family caregiving that a panel of national experts discussed at the closing general session of the Aging in America Conference of the National Council on Aging and American Society on Aging (ASA) in Washington, D.C., in March.

The session opened with an address by Gail Sheehy, the best-selling author of *Passages* and 14 other books, who also moderated the panel discussion. An article previous to this one, published in the May-June 2008 issue of **Aging Today** (available online at www.agingtoday.org), reported on Sheehy's dramatic description of her caregiving experience with her husband, groundbreaking magazine editor Clay Felker. (Felker, age 82, died of cancer in July.)

QUITTING A JOB?

In researching her forthcoming book, tentatively titled *The Caregiver Diaries*, Sheehy said she learned that among the top questions the Family Caregiver Alliance (FCA) hot line receives is, "Should I give up or cut back on my job, or should I move to another part of the country to take care of Mom or Dad?" Sheehy asked Lynn Friss Feinberg, deputy director of the FCA's National Center on Caregiving in San Francisco, what adult children should consider in making this decision.

Feinberg noted that people who examine whether to quit their jobs frequently say, "My parents won't let anybody else help out." She continued, however, "More than likely it's not a good idea. I never want to generalize to everyone, but often when adult children find themselves in the middle, they're not thinking of the loss of Social Security credits if they drop out of the labor force, the loss of savings for their own future retirement. Many wouldn't be able to pay for health insurance for their families, and some research shows that women and men who drop out of the workforce to care for their aging parents are more likely to live in poverty in old age."

Feinberg, who spent the past year as a Heinz Foundation senior fellow providing health policy analysis to Sen. Barbara Boxer, D-Calif., observed that the United States needs more options to obviate caregiving dilemmas such as this one. An encouraging development, she said, is the current governmental policy shift from mainly funding institutional placements to supporting homecare and community-based care. She added, though, "We also have to provide support for the family caregiver. Otherwise, we'll go back to institutionalization, to the old days. That means having paid family leave, so that family caregivers don't have to quit their jobs. Every other industrialized country has this."

Feinberg urged the conference audience to support LTC measures, such as the bipartisan respite care bill that is now in Congress, and to advocate for greater funding of National Family Caregiver Support Act programs, whose funding was limited to only \$162 million for 2008.

A positive development toward support for these and other programs, Feinberg said, is the aging of the

boomer generation, which increasingly is exposing the public to “the severe human toll of long-term caregiving.” In the next two to three years, she went on, “we are poised as family caregivers and advocates in aging to move the issue forward. And if we don’t do it, no one’s going to do it for us.”

CARE COORDINATION

Robyn Golden, director of older adult programs at Rush University Medical Center and 2006–2008 chair of the ASA board, agreed that although the National Family Caregiver Support Act requires greater funding to be effective, its passage was an important step. The key to change, she said, will be for more consumers like Sheehy to advocate for programs that fund care coordination. Sheehy had described her husband’s continual trips to emergency rooms, her having to scramble to find a good-quality rehabilitation hospital only six hours before hospital discharge and other unnecessarily trying demands of the current system.

Golden stressed, “As we move toward resolving issues around care coordination and transitions in care, it’s critical that the family and the person affected by the illness be part of those discussions.” She added, “But I think in terms of the ultimate financing of all this, we’re going to have to continue pushing the envelope to rebalance long-term care, finding ways for families, if they choose to stay at home and care, to get some reimbursement for that. We need to find ways to be more flexible in the delivery of services.” Greater flexibility also needs to extend to lower-income clients, she said, to remedy the “disparity between the haves and have nots” in community care.

The model for care coordination that should be adopted throughout the U.S. healthcare system is in hospice and palliative care, said Kathy Brandt, vice president of professional leadership for the National Hospice and Palliative Care Organization in Alexandria, Va. She said past research has demonstrated that when one of two people with the same diagnosis and similar demographic characteristics is admitted into hospice, that person is likely to live a little longer.

The reason, Brandt said, is that “hospice is the only part of our healthcare system where there’s a team approach” that is mandated. Hospice and palliation programs routinely assess both patients and family caregivers, offering them support and training in care; make house calls to render physical care, including needed prescription drugs and medical equipment; and provide psychosocial and spiritual care, as well as volunteer support. For those in a crisis, care is available around the clock.

Commonly, though, people wait too long to consider hospice because most don’t realize that many patients are released from the program when their condition improves, as happened with political cartoonist Art Buchwald. Hospice tends to seem like a death sentence to many because Medicare requires doctors to certify that they expect a patient ready for the program has six months or less to live. As a result, patients recommended for hospice tend to give up hope of surviving longer, and health professionals often hesitate to suggest enrollment in hospice, Brandt said.

Brandt urged health and service providers to tell families, “Don’t be scared. Hospice doesn’t mean that you’re necessarily going to die within six months, and it doesn’t mean that you can’t have hope.”

Beside hospice care, she said, Medicare should also start reimbursing for palliative care, which is provided to people in the earlier stages of terminal illness. She reported that some private insurers are considering such coverage: “They’ve got to save money; it’s coordinated care, and it’s care geared to keeping people out of the hospital by addressing symptoms, by being available at night and on weekends, and by supporting the teaching of family caregivers.”

CULTURAL COMPETENCE

Family education is especially important in culturally diverse communities, stated Louis Colbert, director of the Delaware County Office of Services for the Aging in the Philadelphia area. For example, he said, although Alzheimer’s disease is especially prevalent among African Americans, “it’s often underreported, and diagnosis occurs much later. This suggests to me that people are not getting the help that they need; they have to struggle on their own.”

He discussed his sister’s resistance to seeking help in caring for their 84-year-old mother, who has multiple conditions, including dementia. “I’m always struggling with [my sister] to avail herself of a caregiver support group. And she always looks at me with this question in her face, as if I don’t get it. I found this to be a common theme, especially in my church, where we have the African American support group,” Colbert said. When he has raised the issue with other parishioners, they have told Colbert, “We don’t do that.” He continued, “My sister often says to me, ‘You know, this is our mother. That is what we do; we take care of our mother. This is what we do.’”

Colbert observed that in many Chinese, Latino and other ethnic communities, mental illness—including dementia—is associated with shame, not only for the individual but also for the entire family.

More broadly, Colbert encouraged providers to recognize differences within various cultures. For instance, he said, “in the Philadelphia area there are 17 different Spanish-speaking countries [represented]. Some of these communities have been there for generations, and some are relatively new. When you think about cultural differences, you think about care, about policy, about planning. It’s a very complex fit.” It is incumbent on the aging network agencies, he said, to make their service options known in culturally appropriate and effective ways to the communities they serve. ❖