TRIMS • THERAPY • NOTES

Caring for caregivers: Preserving the support system of disabled elders

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Jim and Catherine S. are both in their seventies. Because of his wife's stroke 10 years ago, Mr. S. retired early and they have managed well. Mrs. S. is paralyzed on her right side and she has a severe speech impairment. She can walk with a quad cane and care for her personal needs. Mr. S. does the cooking, cleaning, shopping, and gardening, but his growing discomfort and stiffness from severe arthritis are making his usual routine more difficult. Next month, because of Medicare regulations, Mrs. S.'s twice-weekly visits from a speech therapist will end. Mr. and Mrs. S.'s usual optimism has not changed, but they have let the case manager know that they both depend on the speech therapy to keep them hopeful about the future.

Carolyn T. has stayed at home almost every day this year to care for her 95-year-old mother. Knowing that her disoriented, bed-bound mother receives excellent and loving care gives her a great feeling of satisfaction. Ms. T. was relieved when her sister came in one afternoon a week to allow her to go out for a while with a clear conscience. But these visits have stopped since the sister has been under treatment for cancer. In addition to worrying about her sister's health, Ms. T. is feeling the effects of 24-hour, seven-day responsibility for her mother's care. Sometimes she sits down and cries, not knowing what to do next.

These people are facing some of the challenges of caring at home for an elderly impaired family member. Although most elders manage to function much as they have throughout their lives, with little help from others, about 20 percent of those older than 65 must depend on others for care. At this moment, five percent of all elders live in institutions, while at least 15 percent of our older people live in the community although they have significant impairments. The efforts of family caregivers make it possible for a great number of them to remain at home.

There is a pervasive myth that young and middle-aged Americans shirk their responsibilities to the elderly. The fact is that 80 percent of all care received at home by elderly people is provided by family members (Brody and Brody, 1981). Not only children, especially daughters and daughters-in-law, but elderly spouses, siblings, and other relatives come to the aid of an elder who can no longer function independently. They are a human barrier between the elder and the institution, providing personal care, supervision, household management, and emotional support. When asked if they will be able to continue this intensive caregiving, the typical answer is, "So long as I am physically able."

Families have varied reactions when they realize that an elder can no longer live independently, and the pre-existing relationships vary in quality. I shall focus on the needs of family members who serve as primary caregivers to impaired elders. The question of how to assist families achieve their goal of maintaining the elder in the community is being addressed by the Texas Project for Elders (TPE), one site of the National Long-Term Care Channeling Demonstration Project, at the TRIMS Gerontology Center. As part of our effort to provide case management to this population, TPE tries to enable and support family member caregivers. The planners of the project expected to find involved, dedicated families surrounding impaired elders. In its interactions with 953 elders over the past 2-1/2 years, the TPE staff has been astonished by the services family members and occasionally close friends and neighbors perform.

We knew, of course, that the elder cannot be viewed in isolation. The case managers understood that explaining their role to family members was essential and that families would need to be included in planning the care of the elderly client. Training and information were made available to staff members to decrease stereotypic beliefs about how families function in assisting elders. As case managers witnessed family situations in which remarkable dedication was evident, it was helpful for them to know that they were observing normal behavior. Families and clients have been included in case conferences, and family meetings have been arranged by case managers when needed.

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Our case management includes assessment, care planning, and arranging for services. Frequently in-home service provides critically needed help, such as cleaning, cooking, or personal care for the client. Identifying which services can most effectively be provided by others is a critical element of care planning. Even a few hours of help a week can relieve the caregiver of a duty that otherwise escalates exhaustion beyond a manageable level.

Respite care has proved to be an essential service that far too often is unavailable or unaffordable. Case managers have worked with caregivers to persuade them of the usefulness of taking time off. Through a special service expansion fund, workers were hired to come into the home to care for the elder for four hours, eight hours, or longer. An ample dose of respite, such as three nights from 8 p.m. until 8 a.m., can serve to rejuvenate an exhausted, stressed caregiver. Respite works best in two ways: when it can be used to respond to unpredicted circumstances, such as a caregiver's illness or absence, and when it is scheduled ahead of time. Knowing, for instance, that one day a month someone else will be on duty can enable the caregiver to meet daily stresses more calmly.

A support group was established to bring together the caregivers who wanted to share their experiences and seek more information. We hoped that this effort would not only decrease the caregivers' isolation, but would help them to feel more empowered through education on pertinent topics. The group has met for more than a year. During the two-hour meetings, the caregivers check in with one another, a speaker addresses the group and responds to questions, there is a break for refreshments, and time for informal discussion. The educational and support benefits of the group seem to be of equal importance to those who attend.

We send caregivers one-page summaries of past meeting topics with invitations to the next meeting.

We wrote a handbook, *Aging, Living & Caring, A Handbook for Families and Friends,* for distribution to all caregivers associated with the project. It addresses such topics as caregiver guilt and stress, normal aging, and community resources. The book reached even those people who chose not to or were unable to attend the group meetings. Many caregivers said they were surprised and relieved to see that their feelings had been expressed and explained in writing.

The special nature of a demonstration project has allowed TPE to offer several types of caregiver support. Our hope is that other professionals can find ways to emphasize support of caregivers using existing resources in their programs. Caregivers have reacted positively to our staff's recognition that they are performing a difficult job. They have worked with other members of their families to institute respite care by asking for it from one another or jointly paying for it. They say that knowing that others are in the same situation and have similar feelings helps them to continue. They have responded with keen interest to the educational presentations and written materials. It is our strong impression that activities that recognize, relieve, link, and educate caregivers enable them to be more effective in caring for their elderly relatives at a lower emotional and physical cost to themselves.

Brody, E.M., and Brody S.J. 1981. New directions in health and social supports for the aging. In *The Aging: Medical and Social Supports in the Decade of the 80's.* New York: Center on Gerontology, Fordham University.

Correction: In the last issue, a reference to the older benzodiazepines, diazepam or chlordiazepoxide, should have said they have a **longer** (not a shorter) halflife.

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