

What Formal Help Is There for the Transition to a Facility?

Adult Placement Services in County Departments of Social Services

Adult Placement Services help aging or disabled adults find appropriate living and health care arrangements when their health, safety, and well-being can no longer be maintained at home. Adults and their families receive help to complete medical evaluations and financial applications and locate and move to new settings. They also may receive counseling to help them adjust to the change. All 100 county departments of social services provide Adult Placement Services.

Family Caregiver Support Program

Although the mission of this program, housed in Area Agencies on Aging, is to prevent or delay institutionalization by supporting caregivers at home, caregiver support specialists provide information and counseling about services and how to get access to them, as well as sponsoring caregiver support groups and education. Locate the specialist in your area at <http://www.ncdhhs.gov/aging/fcaregr/fcjobs.htm>

Long-term Care Ombudsman Program

A major focus of this program is helping residents understand and maintain their rights in long-term care facilities, and this includes responding to residents' complaints about violations of their rights and offering informal mediation or problem solving to resolve such situations. In addition, ombudsmen answer questions and give guidance to families about the long-term care system, including explaining options; giving pointers on

how to select a facility; providing information on specific facilities; explaining residents' rights and the laws and regulations governing facilities and residents; and providing information about Medicaid and Medicare and such matters as powers of attorney, living wills, and guardianship. Regional ombudsmen are also located in Area Agencies on Aging. Locate your ombudsman at <http://www.ncdhhs.gov/aging/ombud/ombstaff.htm>

Independent Geriatric Care Managers

Among the services provided by these professionals is continuity of care to help families access the services they need, according to the National Association of Professional Geriatric Care Managers, Inc., which licenses them nationally (<http://www.caremanager.org/index.cfm>). You can search their website for care managers in your area.

Elder Law Specialists

The National Academy of Elder Law Attorneys (<http://www.naela.com/>) is a membership organization that provides information to attorneys and others who provide legal services to older and disabled adults and their families. Among the services elder law attorneys provide is assistance in planning for long-term care. You can search their website for elder law attorneys near you.

More Information

Visit the CARES website for a supplement to this issue containing links to information, references, and resources for professionals and family members.

<http://ssw.unc.edu/cares/caregiving.htm>

ASPN: Adult Services Practice Notes

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The aspen is perhaps the world's largest organism. Although some aspen forests cover acres and seem to be composed of individuals in all stages of life, they share a common root system.

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Adult Services Practice Notes

Dedicated to providing information on excellent family-centered practice with adults and their families.

After Placement

Who Cares for the Family Caregiver?

Negotiating the change from caring for people at home to caring for them in a facility has its own steep learning curve and emotional heavy lifting, and that's the subject of this issue of ASPN. Family caregiving is the backbone of long-term care in the US, and maintaining people with disabilities at home for as long as possible is something both care recipients and caregivers value highly. However, despite heroic efforts on the part of caregivers, many care recipients eventually need institutional care. In 1997, Kemper and Murtaugh estimated that about a third of men and half of women age 65 and older will spend at least some time in a nursing home. The move to assisted living or a nursing home is a decision and process that many families will face, particularly as care recipients age into their 80s.

Family caregiving doesn't end with the care recipient's entry into a facility, and making the transition can be difficult not only for the people making the move but for the caregivers. The transition usually brings with it new challenges and stresses for everyone concerned. Schulz and Beach reported in 1999 that caregiving itself is a risk factor for sickness and death, regardless of any other conditions the caregiver may have. In 2004, Schultz and colleagues studied families caring for people with dementia and found that rates of depression among caregivers remained the same before and after placement, while rates of anxiety actually increased. They found that rates for both depression and anxiety were higher among spouses than among other family caregivers, and that caregivers who felt they had poor support from family and friends before placing their relative had a more difficult time with the transition.

If you think about it, community support for caregivers and acknowledgment of their efforts often stops at the door of the nursing home or assisted living. Sometimes family and friends may say, "Aren't you relieved now that someone is looking after him?" Service providers are paid for services to the care recipient, but not usually for following up with the caregiver. Social workers in residential care facilities can offer support to caregivers, but not all facilities employ them, and their first concern may be the new resident.

We would like you to let the experience of Mr. and Mrs. M spark your thinking about how your agency—or your faith or civic organizations—already helps or might help caregivers through this stressful time. The Ms were financially better off than many families, had done some advanced planning, and in some cases were just lucky, but many of the challenges they faced could not be solved with money, planning, or luck.

What resources are there in your community to help with the practical and emotional changes caregivers face when institutionalization becomes necessary? If you are a caregiver in this situation, what do you need, and where do you turn to get it? The last page lists some public and private sources of help, but we can do more in our communities to assist caregivers in making this difficult transition. Visit the CARES webpage at <http://ssw.unc.edu/cares/caregiving.htm> for links to additional information.

Managing the Practical Aspects

Medical Care

People who enter long-term care facilities must select a primary physician to visit them at the facility, and often this is the facility's medical director. They may continue to see other physicians who have been involved in their care, but changes in medication or treatment must be coordinated through the new physician and facility's nursing staff, who don't have a history of working with the resident and family. Mr. M lost contact with Mrs. M's previous doctors because he was worried that if he took her out of the facility to appointments, she would insist on going home, rather than back to the facility. Both of them had to develop new relationships with her new health care providers. Another source of stress for caregivers—particularly those who have learned how to manage complicated medical procedures or medication at home—is whether their family members are getting what they need when they need it. The unit manager reported Mrs. M's blood sugar and weight to Mr. M each day when he visited, which helped develop a level of trust about her care.

Paying for It

The Ms were among the few who had ample resources to pay for care. Most families aren't so fortunate—a major source of stress can be finding an affordable facility and identifying how to pay the bill. Medicare pays only for short stays in facilities for rehabilitation. Medicaid pays for about 70 percent of institutional care for older people, but “spending down” to qualify for Medicaid can take years, and some people find themselves in the difficult position of not having enough income to pay for care but having too much to qualify for assistance. Having more financial resources often allows more choice, but finding a suitable facility takes time and is stressful, regardless.

Visiting

The care manager helped the Ms find a suitable facility that was an easy drive from their home. Getting there, however, may be a large problem for any caregiver, because of the travel time, work schedule, expense, or lack of transportation. Caregivers often have to juggle their schedules to visit, decide how often to go, and fit this into the routine of the facility. Family members also may not know what to do when they visit, particularly if their family member has dementia.

Learning What Care to Provide

Early on, the CNAs explained to Mr. M that bringing incontinence supplies and personal care items would be cheaper than buying them at the facility. Because he visited daily, he could restock as necessary, and this was a straightforward type of care he could continue to provide. More frustrating though, he spent some part of every visit locating Mrs. M's glasses and hearing aids and checking her clothing supply.

Planning and Advocating for Services

When Mrs. M entered the facility, Mr. M did participate in the care planning meeting and completed a lengthy questionnaire about Mrs. M's habits and preferences. Although the discharge summary recommended physical therapy, he discovered that she wasn't receiving it regularly. He was reluctant to ask about it at each visit—it seemed like nagging, and some days the unit manager wasn't available. He found it easier to arrange for Mrs. M to have her hair done once a week in the facility's beauty shop—something she had enjoyed when she was still at home.

Planning for the Future

One necessary, if difficult, part of the move is contingency planning. Long before Mrs. M showed symptoms of her disease, the couple had made wills and advance directives, and assigned a durable power of attorney and a health care power of attorney. It is important to identify someone who can be responsible if anything happens to the caregiver and take steps to be sure that person can get access to financial and medical information.

Mr. and Mrs. M: A Brief Case Example

Mr. and Mrs. M had been married for more than 50 years when Mrs. M began to develop dementia. Both had had long, successful professional careers and had retired in their 70s. As children of the Depression, they had lived well, but frugally. As Mrs. M's disease developed, Mr. M took care of her at home, slowly assuming more responsibility for managing the house. Her behavior became disruptive, and after she was hospitalized for a mild stroke, he accepted the advice of their geriatrician and geriatric care manager that she should be discharged to the dementia care unit of one of the local assisted living/nursing care facilities. Here's a brief look at some of the challenges he faced when he made the transition from caring for her at home to caring for her at the facility.

- Although Mrs. M had seen a number of physicians in the hospital, including her usual one, once at the facility, she was in the care of a new doctor. She had adult-onset diabetes, so Mr. M was concerned that she was getting her insulin correctly and that her diet was appropriate.
- Early in her stay at the facility, Mrs. M had gotten out of the unit on her own and gone to the main entrance, where she asked someone to call her a cab so she could go home.
- The director of the unit spoke American English, but none of the CNAs were native speakers of English. However, they were from diverse enough backgrounds that for many of them, English was the language they had in common. They were as culturally diverse as their languages and had little cultural common ground with the White middle-class women in the unit. Mr. M, who was an introvert, had to learn how to communicate and interact effectively with his wife's caregivers.
- Mr. and Mrs. M didn't have a network of friends—Mrs. M had been the more outgoing of the two, and as her disease progressed, they became more isolated. Their children lived far away and mostly had contact by telephone. Shortly after Mrs. M entered the facility, the geriatric care manager said she could no longer work with them because she had to help her own parents move in with her.
- The facility did have a family council that met at least monthly, and though his children encouraged him to participate, Mr. M said he “wasn't interested in doing things like that.”
- The Ms were unusual in having a retirement income large enough to cover the cost of Mrs. M's care without causing Mr. M any hardship. Although Mr. M didn't have to worry where the money was coming from, he did have to manage it—paying for care in the facility, sorting out payments from Medicare and their coinsurance for her hospitalization, as well as Medicare payments for her medical needs at the facility.
- Mr. and Mrs. M had made wills and advance directives about their care, as well as giving the child who lived closest durable power of attorney and health care power of attorney.
- Unlike many men of his age cohort, for whom household responsibilities were assigned by gender, Mr. M was used to housekeeping tasks—he could cook and clean and do laundry. However, even though she needed supervision, Mrs. M had still done or helped with many of these tasks, and when she was gone, he had to do them all for himself, as well as his “usual” outdoor tasks.
- The facility was about five miles from his house, and Mr. M went to visit every morning. However, because he kept this schedule, he stopped doing some the activities that had kept him connected to his former work life and colleagues.

Managing the Emotional Aspects

Developing Trust

In the first week of her stay, Mrs. M almost walked away from the facility, and shortly after that, she fell and hit her head, leaving a large bruise. Apart from concerns about the management of her medications and diet, Mr. M also had to judge whether she would be physically safe in this new setting (and it wasn't looking good). It takes time for caregivers to judge either the quality of care or the degree of trust the place merits, and they may have no basis for comparison.

Developing New Relationships

Because Mr. M was not a very sociable person, this might have been more difficult for him than for some other people. Nonetheless, caregivers relinquish control and have to negotiate with others about the care of their family members, rather than just making decisions and acting on them. Some may have considerable difficulty learning how to negotiate effectively.

Another complication that may be fairly widespread is the ethnic, cultural, and linguistic differences between the staff of the facility, the new resident, and the caregiver. All may have very different expectations about how older people are treated and cared for.

Caregivers of people at home or in institutions may benefit from support groups or from participating in the facility's family council. As with Mr. M, this strategy is not for everyone, and these groups are not always available (but check your local senior center and religious congregations). For those with computers, there are now online groups that may be more convenient. It's important to help caregivers identify what support does work for them.

Changing Roles and Tasks

Unlike many men of his generation, Mr. M had learned how to clean house, iron, and cook. Managing a household took more of his time than it had before, but he didn't have to learn a whole new set of skills. Many older men, however, may not know how to do these things (and be embarrassed to ask), while many older women may suddenly be faced with managing finances, maintaining cars, or mowing the lawn—things their husbands formerly did.

Although residents in long-term care have the right to privacy, for spouses the transition of one of them to a facility brings a substantial change in physical aspects of their relationship, one that is rarely discussed. Losing touch (quite literally) can be devastating for both partners.

Coping with Guilt, Anger, and Loss

Research tells us that caregivers who place their loved ones in a nursing home experience far greater grief than those whose loved one dies at home. Guilt is a major source of stress when their family member enters a facility, because caregivers worry that they have somehow not cared enough or that they could have done something to prevent placement. Caregivers also often feel anger—at the person they're caring for, at other kin who didn't share the caregiving, or at a social system that seems to place economic hardship on them.

It's hard to identify an area where caregivers do not suffer loss—to their identity as a caregiver (they still are, but often not recognized as such), to their role in the family, in their relationship with the care recipient and with other family members, to their control of the situation, and very often to their financial well-being and time. Many realize that the move signals the last phase of their family member's life and go through anticipatory grief or real bereavement.

The Bottom Line

The sad ending to this story is that about a year after Mrs. M entered the facility, Mr. M died suddenly of a heart attack. He had visited his cardiologist regularly and took his medications. Did caregiving stress play a role? In a person his age, it's hard to tell, but it's quite possible. Placing a family member isn't the end of caregiving, and providing care for someone in a facility doesn't relieve stress. We need to find ways to acknowledge and support these hidden caregivers.