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

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 may also 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 programs provide information and counseling about services and how to get access to them, as well as sponsoring caregiver support groups and education. You can 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, ombudsman 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 your 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 your 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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Who Can Help with the Practical and Emotional Changes Caregivers Face? 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, Schulz 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.

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, Schulz 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.

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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 been managing his heart condition successfully, but a major event had triggered his death. This event was a sudden and unexpected loss for the community and for other caregivers who had worked closely with Mrs. M.

The Bottom Line

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 married to a noncaretaker 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 to give rather than receive.

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.

Visiting

Mr. and Mrs. M had an active social life together when they were care-giving. But when she entered the facility, he had to learn the routines of her new living situation and how to respond to her as a new person.

Planning and Advocating for Services

Planning to leave the facility, Mr. M participated 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 that if he gently suggested 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 entered the facility, Mr. M had participated 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 that if he gently suggested 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.

Managing the Emotional Aspects

Developing Trust

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