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# ASPN

## *Adult Services Practice Notes*

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

# Family Caregiving

Family caregivers are the heart of your day-to-day work, whether we're talking about clients you serve directly or communities whose services you plan or implement. But what about your colleague at the next desk or down the hall? What about you? Are you a caregiver, too? According to the Centers for Medicaid and Medicare Services, about a fifth of the households in this country—that's 44.4 million people—are involved in taking care of an adult (who may or may not be related by blood or marriage). About 40% also care for children, and 15% of caregivers live an hour or more away from the person for whom they're caring. Odds are that while you are helping family caregivers, you and your colleagues are facing the same challenges yourself.

The "typical" caregiver for another adult is a 46-year-old woman, married or living with a partner and working, but about 40% of caregivers are men, who are even more likely to be working full or part time. The large majority of care receivers are over 50—often the mother, father, or grandparent of the caregiver—but 20% are between 18 and 49.

Your role may be to help families find assistance in caregiving, but only 41% of caregivers have paid aides or respite. About a third provide all the care, without any informal help. Not surprisingly, this produces a lot of strain.

Caring employers and communities can make it possible for families to help their members live at home as long as possible. As employees of the principal public and private organizations that work with older and disabled adults, you play a crucial role in identifying strengths within your community, as well as needs, and advocating—not only on behalf of your clients but for your own family, now or in the future. In this issue, we'll look at several aspects of caregiving: How to help families discuss and resolve conflict, how employers can support family caregivers, and resources for your clients and families and maybe yourself.

## Helping Caregivers Resolve Conflicts

by Kathy Lowe, MSW

As people reach older ages, many live with infirmity for some months or years, requiring care from another person to sustain their quality of life. About 80% of us will experience a slow decline in functional ability before we die, and our children, spouses, grandchildren, and friends may become our caregivers, as we now care for the current older generation. Sometimes family caregivers have differing opinions about the form that care should take, and conflict arises, not only about roles and decision making, but about the implications of the situation for the care recipient and caregivers.

## Facing Reality

As hard as it may be to recognize and face up to the changes in our own bodies

*Continued, p. 2*

## Resolving Conflict, continued

as we age, it is sometimes even harder for the people who love us to acknowledge those changes or for us to accept them in those we love. Caregivers may seem oblivious to things that seem obvious to everyone else familiar with their situation. A recent issue of *ASPN* outlined the stages of change, and they apply to most adjustments to new situations. Adult children often need to continue to see their parents as the independent people they used to be, even when the situation has changed substantially. Denial, grief, or guilt can make it difficult for them to assess parents' abilities—whether over- or underestimating them. Differences in where caregivers and care receivers are in adapting to change can be the source of heated conflicts.

Among the most difficult decisions facing people are whether to stop driving, whether to change where they live, and how to face the end of life. Decisions about these issues are often delayed until there is a crisis, but this isn't the way to get the best resolution. One of the most helpful things you can do in your work with families (and in your own family) is to encourage advance planning, based on your assessment of where the various members are in their process of adapting to change. Perhaps you can help family members move to the next stage, by providing information or making referrals or just listening and gently challenging mistaken perceptions. With clients who are receiving care, helping them make their wishes known to their families may be the most helpful thing you can do, and it is certainly a great gift to their caregivers.

## Roles

Who is identified as the primary caregiver? How much autonomy and self-determination does the person receiving care retain? What kind of say do other friends and family members have? Members of the caregiving "team" may have divergent opinions about this issue, stemming from their individual personalities, relationship to the person receiving care, individual level of comfort with the situation, and need to "fix the problem." For example, you might be completely comfortable allowing your client (or your mother?) to retain responsibility for those areas of her life that she continues to handle well, only intervening where there is a gap in her capabilities. Your client's son (or perhaps your brother) may prefer a more preemptive approach, to protect her from harm. How the two caregivers negotiate this situation and whether their mother is involved in that discussion will be critical to avoiding a conflict.

## Decision Making

One of the best ways to avoid conflict among caregivers is to plan while care receivers are still able to

make their wishes known. They can do this by completing a will, health care power of attorney, living will, and durable power of attorney, so that loved ones don't have to guess about what they really wanted. Just as important, though, is to tell family members that these documents exist and where to find them, share what decision-making process has been put in place, and talk about the general and specific wishes they contain. Then, if the family is faced with a situation where they must intervene, it will already be clear who has the authority to make decisions, and others may understand the basis for these decisions.

## Facilitating (and Holding) Productive Family Meetings about Caregiving

When a family gathers to discuss caregiving issues, these techniques may promote a positive outcome.

1. Use the care receiver's definition of *family*, which may include people not related by blood or marriage, when including stakeholders in the meeting.
2. The person receiving care should lead the discussion whenever possible and be included, if leading the discussion is not possible. The family may opt to discuss issues without the care receiver, but including him or her will help the family focus on that person's needs and desires.
3. Help the family select a neutral location for the meeting to avoid anyone controlling the discussion by virtue of hosting the gathering. A conference room at your agency might be appropriate, if there is one large enough to hold everyone comfortably.
4. Be the neutral facilitator for the discussion. For discussions within your own family, find someone to facilitate who has no stake in the outcome.
5. Help participants focus on present issues and avoid being sidetracked by old disagreements and events.
6. Acknowledge feelings, not just facts.
7. Allow everyone an uninterrupted opportunity to speak.
8. Aim for a common understanding of the situation and collective ownership of the plan of action. Avoid putting emphasis on positions—that is, what individuals see as solutions ("Mom should go to a nursing home"), and strive to identify common interests ("We are all concerned about Mom's safety"). This will provide more agreement on goals and leave room for discussion of different strategies.

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See V. L. Schmall, M. Cleland, and M. Sturdevant, *The Caregiver Helpbook: Powerful Tools for Caregiving*. Chapter 7 provided the springboard for this list.

*Kathy Lowe joined CARES as an education specialist in September 2004. Meet her at our upcoming training events.*

## How (and Why) Should Employers Support Family Caregivers?

Although the care provided by families is “free,” it is costly care. One estimate of its value—what it would cost to replace it with paid care—is over \$250 billion a year nationally. Another measure of its value is what it costs businesses and nonprofit organizations: somewhere between \$11 billion and \$29 billion estimated for 1997, certainly more now, as baby boomers and their parents age.

Why so large a cost? Caregivers often must interrupt their work, take leave, reduce their hours, and even stop working altogether, all of which are expensive in terms of lost productivity, lost job-related knowledge (how long did it take you to learn how to do what you do?), and the cost of recruiting, hiring, and training replacement workers. This is as true of your agency and its personnel as it is of the businesses in your community. Depending on which source you consult, it can cost almost as much as an annual salary to replace an employee, and vacant positions put additional strain on other employees.

Caregiving is costly for caregivers, too. Many report providing money as well as time, but more important, those who stop working to provide care can lose hundred of thousands of dollars in wages, pension benefits, and Social Security, putting their own financial well-being at risk.

### How Employers Can Help

Information is often the caregiver’s biggest need and one that costs relatively little to provide. At a minimum, employers can make available a brief list of sources of information and contacts for services available in the community. A more family-centered organization might provide

caregiver training or information sessions at work, adopt flexible schedules or work locations, or even provide or subsidize adult day services. However, many who provide care don’t identify themselves as caregivers, perhaps because they don’t recognize themselves in that role or because they’re worried about consequences of revealing it.

North Carolina has a well-developed website with information for caregivers and professionals. Visit Full Circle of Care, <http://www.fullcirclecare.org>, developed and maintained by the Triangle J Area Agency on Aging, for a wealth of information about caregiving, assistance and services available, and training for caregivers. The site also provides links to other states’ coordinating agencies, as well as to the federal Eldercare Locator, 800-677-1116. See the list of the state’s family caregiver support specialists, who provide information and training to caregivers in each county.

### Some Helpful Resources

Duke Family Support Program, “Absent on the Job,” <http://www.dhhs.state.nc.us/aging/fcaregr/absentonjobl.pdf> (This report provides up-to-the minute information on working caregivers and how employers can assist them.)

Family Caregiver Alliance, <http://www.caregiver.org/caregiver/jsp/home.jsp> (A wealth of information. See in particular their handbook for distant caregivers and their information sheets for caregivers on caregiving, medical issues, and legal issues, some in Spanish and Chinese.)

National Alliance for Caregiving: <http://www.caregiving.org> (Data in these articles are drawn from their reports. See *Caregiving in the US* and *Miles Away* [2004], and also their tips for caregivers.)

NC Cooperative Extension Service, “Planning Your Estate,” <http://www.ces.ncsu.edu/depts/fcs/estates/index.html> (See in particular the chapters on discussing end-of-life issues, the basic documents, and the various powers of attorney.)

NC Division of Aging and Adult Services, Family Caregiver Support, <http://www.dhhs.state.nc.us/aging/fcaregr/fchome.htm>

### Are You Working with Long-distance Caregivers?

Like caregivers who live near their care recipients, information is what long-distance caregivers need most, although often it is a bit more detailed and personal, and if you provide it, you’ll have to get permission from your client. Distant caregivers often want to know about the care receiver’s status, what services are appropriate and available, whom to contact in an emergency and for regular updates, and legal issues. Much of the same information you collect as part of client assessment would be helpful to caregivers, from such standard data as Social Security Number and primary physician’s name and contact information to current medications and relevant medical history to location of such legal documents as birth and marriage certificates, powers of attorney, and wills.

Beyond that, caregivers need more general information on current functioning, diagnoses and their likely consequences, and how to plan for the future. DSS and other human services workers often provide this assistance, as do private care managers. You might want to work with your client to develop an information sheet or handbook for caregivers like the model developed by the Family Caregiver Alliance (see the box for their web site), containing basic information, as well as helping clients and distant caregivers identify reliable local day-to-day and emergency contacts.

*North Carolina became the fourth most popular retirement destination at the 2000 census, after Florida, Arizona, and Nevada.*

## Family Caregiver Support Specialists by Region

The Family Caregiver Support Program (FCSP) is a federally funded program administered through the 17 Area Agencies on Aging (AAA). This program provides resources and public awareness about caregiving. It targets caregivers of persons age 60+ and has limited funds for older grandparents or other relatives raising children under 18. The program's flexibility allows for a variety of service delivery options from one county to another. To find out more about the FCSP in your county, call the caregiver resources specialist at your AAA.

- A** Tamara Young (828) 488-9211 x3033 (Cherokee, Clay, Graham, Haywood, Jackson, Macon, Swain)  
**B** Carol McLimans (828) 251-6622, x 115 (Buncombe, Henderson, Madison, Transylvania)  
**C** Michelle Templin (Cleveland, McDowell, Polk, Rutherford) (828) 287-2281, x 1258

- D** Saran Craig (828) 265-5434 x128 (Alleghany, Ashe, Avery, Mitchell, Watauga, Wilkes, Yancey)  
**E** Virginia Parrish (828) 485-4256 (Alexander, Burke, Caldwell, Catawba)  
**F** Ronda Deitch (704) 348-2738 (Anson, Cabarrus, Gaston, Iredell, Lincoln, Mecklenburg, Rowan, Stanly, Union)  
**G** Blair Barton-Percival (336) 294-4950 (Alamance, Caswell, Davidson, Guilford, Montgomery, Randolph, Rockingham)  
**I** Beth Rummage (336) 761-2111 (Davie, Forsyth, Stokes, Surry, Yadkin)  
**J** Ellison Jones (919) 558-9391 (Chatham, Durham, Johnston, Lee, Moore, Orange, Wake)  
**K** Michael Rood (252) 436-2040 (Franklin, Granville, Person, Vance, Warren)  
**L** Debra Kleesattel (252) 446-0411 (Edgecombe, Halifax, Nash, Northampton, Wilson)  
**M** Sherri Snipes (910) 323-4191 x28 (Cumberland, Harnett, Sampson)



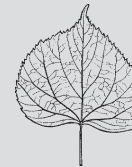
**Full Circle of Care**  
<http://www.fullcirclecare.org>

- N** Anne Oglesby (910) 618-5533 x3006 (Bladen, Hoke, Richmond, Robeson, Scotland)  
**O** Holly Henderson (910) 395-4553 x204 (Brunswick, Columbus, New Hanover, Pender)  
**P** Jody Riddle (252) 638-3185 x3015 (Carteret, Craven, Duplin, Greene, Jones, Lenoir, Onslow, Pamlico, Wayne)  
**Q** Sallie Williamson (252) 974-1800 or Alison Phlegar (252) 974-1838 (Beaufort, Bertie, Hertford, Martin, Pitt)  
**R** Catherine Smith (252) 426-5753 (Camden, Chowan, Currituck, Dare, Gates, Hyde, Pasquotank, Perquimans, Tyrrell, Washington)  
**State** Chris Urso (919) 733-8400 x208 (NC Division of Aging and Adult Services)

Visit the CARES web site at <http://ssw.unc.edu/cares/cares.htm> for on-line copies of this newsletter, updated calendar of workshops, links to background materials for events, and much more.

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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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