

# Family Care and Alzheimer's Disease

## What Do We Know? What Can We Do?

*Lisa P. Gwyther, MSW, LCSW*

### Alzheimer's Family Care: What Do We Know?

**A**lzheimer's family care is intense, personal, and unrelenting. It has been compared to running a marathon without ever seeing the finish line. Alzheimer's has forced long-term care services and policy to move from a narrow "aging" focus to a "family" focus that is more inclusive of the person with dementia as well. National public awareness campaigns have accelerated recent consumer trends. Families as consumers and surrogate decision makers for their impaired relatives are demanding earlier and more comprehensive diagnosis and treatment of Alzheimer's or a related disorder. This growing family recognition of Alzheimer's costs to multiple generations is becoming clear to the public in advance of business and policy recognition.

Family care definitions have also moved beyond blood and co-residence to be more inclusive of other informal or faith-based community support programs and working family members who frequently become long-distance care decision-makers and care managers.

Research estimates suggest that 30% of persons with moderate to severe dementia live alone in the community, often relying upon close supervision and direct help from family members, neighbors, or friends who live close-by.<sup>1</sup> Primary, secondary, and even tertiary family caregivers have been identified in studies of diverse ethnic and racial groups caring for persons with Alzheimer's.<sup>2</sup> In contrast to persistent myths of family abandonment, research consistently finds more Alzheimer's family care in hospitals and nursing homes than at any time in

our history, with persistent documented negative effects on family caregiver mental health even after nursing home placement or death of the person with dementia.<sup>3,4</sup> Although persons with Alzheimer's disease living alone or in nursing homes are more likely to be older women who have literally outlived all family support, 70% of nursing home residents have involved family caregivers and the majority of these residents have some form of dementia.

Even in the best of families, for whom Alzheimer's care is knowledgeably and willingly undertaken, and when there are personal testimonials about meaningful gratification in providing such care,<sup>5</sup> the "wear and tear" and prolonged strain of constant supervision have been shown to have negative consequences on health, family relationships, and future financial security of surviving family members. Research on Alzheimer's family care

was the first to document the significant proportion of male (primarily husband caregivers) often overlooked in general studies of family caregiving as a predominantly women's issue.

We have long known that there is increased risk of late-onset Alzheimer's disease when one has two or more first degree relatives with Alzheimer's. Not only do Alzheimer's families face personal fears and

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risks of heritability, but they also face documented risks to their physical and emotional health from providing care. Providing more than nine hours of care per week for a relative with Alzheimer's disease has been associated with a two-fold increased risk relative to non-caregivers of coronary heart disease (CHD), hypertension, poor immune function, slow wound

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**Lisa P. Gwyther, MSW, LCSW**, is an Associate Clinical Professor in the Department of Psychiatry and Behavioral Sciences at Duke University Medical Center in Durham, North Carolina. She directs education for Duke's Bryan Alzheimer's Disease Research Center and she directs the Duke Aging Center's Alzheimer's Family Support Program. She can be reached at lpg@geri.duke.edu or 3600 DUMC, Durham, NC 27710. Telephone: 919-660-7510 or toll-free at 800-646-2028.

healing, low perceived health, depression and anxiety, exacerbation of chronic illness, and even premature death.<sup>6</sup>

Physicians also hear from anguished family members fretting from afar about relatives with dementia. One son laments,

How can I know what's really going on? When I call, they say "we're fine," but I see changes. When I make suggestions to my sister, she reacts with "why don't you take them?" Crisis calls tear me up. I'm helpless, trapped, grieving. I catch myself relieved to be 3,000 miles away... and guilty about it.

Even families who have resources for extensive medical treatment and personalized home care still wonder, as Reeve Lindbergh did in caring for her mother, Anne Morrow Lindbergh, when she was dying with dementia,

No matter how good the medical care, attention or money lavished on our beloved mother... we feel guilty because our presence doesn't seem to help... it is never enough.<sup>7</sup>

The Duke Aging Center's research on Alzheimer's family care documents that families make decisions about use of paid or voluntary services based on subjective perceptions of whether help from other family members or friends is "dependable, sufficient, or enough." Older spouses often "wait" for physician "prescriptions" for outside help, and they are frequently disappointed by cavalier recommendations to "look for nursing homes," which many families perceive as medical abandonment. Each family member has his/her own definition of what constitutes "dependable and sufficient quality care." This variability and complexity among family caregivers limits the effectiveness of Alzheimer's "disease management protocols" applied outside the context of family assessment. Practice guidelines for Alzheimer's disease management must consider care context as well as patient variables.

## Alzheimer's Family Care Is Complex

Although no two family care situations will necessarily respond to a single, linear disease management algorithm or protocol, each family caregiver at some point will have to:

- Define and negotiate complex situations and decisions: Whose needs? How much help is adequate or enough? How long can we provide this level of help? How can we evaluate quality, safety, risks, cost, and benefit?
- Perform physically intimate tasks made more difficult because of resistance, fear, or misunderstanding by the person with dementia.

- Manage emotions and communication as the person with dementia becomes less able to manage his or her emotions and communication.
- Modify expectations of one's family, oneself as caregiver, the person with dementia, physician, and social support services.
- Capitalize on the person with dementia's intact remaining skills and abilities.

In the process of providing family care, individual family members may become the person with dementia's confidante, protector, enemy, constant companion, information seeker, care manager, consumer advocate, surrogate decision maker, and healthcare provider in no particular order.

## High-Risk Family Care Profiles

There are known high-risk profiles for Alzheimer's family care that are not amenable to health or social interventions. Family caregivers who co-reside and provide a high or intense level of direct care or supervision, especially low-income or low-education female caregivers over 50 years old who perceive no choice in a decision to care, or frail older wives, are most vulnerable to negative outcomes from providing Alzheimer's family care. Studies further confirm modifiable risks associated with negative outcomes of Alzheimer's family care that are amenable to health and social support interventions: high depression and anxiety, impaired self-care and health behaviors, safety issues, inadequate social support (social isolation vs. engagement), and the challenging behaviors, personality, and communication changes of the person with Alzheimer's. Adult children who provide care out of financial necessity pose additional risks for the person with Alzheimer's from fraud, exploitation, abuse, or neglect. Often families providing care are at risk simply because they lack health literacy, knowledge of or access to information and support, or because they have personal health/mental health conditions that limit their capacity to provide quality care.

### Box 1. Just for Families: Ten Things to Know

- 1 The desire to avoid thinking about what you are facing is normal, but you can get beyond it.
- 2 The process of the disease is not completely predictable. Other things happen. Your family member will need more help over time, and you may be forced to make decisions that he/she will not like.
- 3 The person with AD can still, and needs to, do many things for you.
- 4 The person with AD is doing the best he/she can. Trying harder is frustrating and doesn't work.
- 5 You, not your relative, will have to change.
- 6 Your emotional relationship with each other will change despite your continued love and willingness to help.
- 7 Grief comes with this process of loss.
- 8 There is no single right or wrong place or time to care or care plan.
- 9 This is the rainy day for which you saved.
- 10 There is life beyond and after Alzheimer's care.

## **Personal and Social Costs of Alzheimer's Family Care**

The most commonly cited personal costs of Alzheimer's care are feelings of being overwhelmed, alone, fatigued, depressed, anxious, angry, and suffering from exacerbated chronic conditions or stress-related illnesses. Often, families report the premature death of the primary spouse caregiver necessitates a sudden change in both the care location and primary caregiver, disrupting entire families. Further, families report social costs of Alzheimer's disease care as loss of valued friendships and community activities; family conflict and guilt; less personal time and privacy; and prolonged bereavement, loss, and sadness.

## **Successful Coping with Alzheimer's Family Care**

The Duke Aging Center's Alzheimer's caregiver studies provided early evidence of successful coping strategies of North Carolina families. The majority of North Carolina families reported reliance on a strong religious faith, belief system, or practice. In addition, caregivers who successfully modify expectations and re-appraise their efficacy ("good enough for now" solutions) report success in adapting over the disease trajectory. Other successful coping strategies include enhanced self-care and health behaviors, reducing rigid or inflexible behaviors, using humor, dependable family support, respite options, energy economies, forgiveness strategies, ingenuity, problem-solving, expressive, and advocacy outlets.

## **Key Decision Points for Physician Intervention: Transitions in Care**

Transitions in illness symptoms and care are especially vulnerable times for persons with dementia and their family decision-makers. It is at these times that families are most likely to turn to physicians as gatekeepers. These transitions (see column to the right) in care highlight common hazards in family decision-making around Alzheimer's disease.

Families are often forced to make decisions in the face of an unrelenting series of crises without time to sort through conflicting perceptions and expectations. We know stressed individuals are at a disadvantage in decision-making and, for many families, Alzheimer's care is only one of a number of pressing family crises. Families may rigidly adhere to old promises that are no longer situationally relevant. Families may wait for the person with dementia to ask for help, chasing the ghost of the person as someone with intact judgment and executive function. Family decisions may await direction from a physician and often that direction is not framed in a way to facilitate a choice between equally unattractive options. Families may also delay

## **Box 2. Nine Strategies for Alzheimer's Families**

- 1** Being reasonable, rational, and logical will just get you into trouble.
- 2** People with dementia do not need to be grounded in reality.
- 3** You cannot be a perfect caregiver.
- 4** Making agreements with the person with dementia doesn't work.
- 5** Doctors need your input on what's really going on and what works.
- 6** You can't do it all. It's okay to get help before you are desperate.
- 7** It is easy to both overestimate and underestimate what your relative can do.
- 8** Tell, don't ask.
- 9** It is perfectly normal to wonder about the diagnosis when the person has moments of lucidity, insight, and good judgment.

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acting on safety issues for fear of losing control of their relative's care to public or agency services. Finally, we know from clinical experience that families may delay decisions based solely on cost, on preserving assets for future generations, or from fear of the stigma and loss of privacy associated with the overwhelming disclosure required for eligibility and service determinations.

The following are examples of transition times where physicians can help families make difficult decisions and find ways to sustain their caregiving capacity:

- Diagnosis (reluctance to seek or accept early diagnosis by the person with dementia or family)
- Changes in driving (getting lost), handling money, taking medications, or alcohol use
- Decisions about the safety of living alone (fraud, neglect, exploitation—see Box 3)
- Decisions about hospitalization, surgery, diagnosis, and treatment of co-morbid conditions (Are symptoms and/or injuries attributable to dementia or signs of another acute illness, medical emergency, or delirium?)
- Decisions about the use of antipsychotics, antidepressants, anxiolytics, sedative hypnotics, and other psychiatric medications
- Changes in primary caregiver
- Need for constant supervision (respite options, in-home help, or day services).<sup>8</sup> See Box 3 for suggestions on how to determine need for constant supervision.
- Residential/assisted living care
- Skilled nursing facility care
- Palliative care and/or hospice care options

Physicians may use these transitions or decision points in care as opportunities to focus education on the most pressing family issues. The timing and "dosing" of information in a way that will not overwhelm patients and families may be just as important as the timing and dosing of medications.<sup>9</sup> Selecting educational strategies—brochures, websites, verbal directions, or referral to an Alzheimer's Association Helpline—should be done with sensitivity to literacy, culture, and capacity of the

family caregiver. See examples of brief family caregiver reminders in Box 1 and Box 2. The geriatric prescribing axiom of “start low, go slow, and repeat often” is relevant to communication and family education around transitions in Alzheimer’s care.

## Key Messages for Alzheimer’s Family Caregivers

- Be willing to listen to your relative, but understand that you cannot fix or do everything he or she may want or need. Know that it will not necessarily get easier, but things will change, and the experience will change your family forever.
- You are living with a situation you didn’t create, and your relative doesn’t like it any better than you do. Your choices may be limited by circumstances beyond your control. Seek options that are good enough for now.
- You can only do what seems best at the time. Identify what you can and will tolerate, set limits, and call in reinforcements. Doubts are inevitable.
- Find someone or a support group with whom you can be brutally honest, express your feelings to them, and move on.
- Solving problems is much easier than living with the solutions. It is tempting for distant relatives to second-guess or criticize. Hope for the best, but have contingency plans for the worst.
- It is not always possible to compare how one person handles things to how another relative would handle it if the positions were reversed.
- Your relative is not always unhappy or upset because of what you have done. He or she is living with unwanted dependency. Sick people often take out their frustration on close family members.
- Considering what is best for your family involves compromise among competing needs, loyalties, and commitments. Everyone may get some of what he or she needs. Think twice before giving up that job, club, or church group. Make realistic commitments and avoid making promises that include the words *always, forever, or never*.
- Find ways to let your relative help or give to you. He or she needs to feel purposeful, appreciated, and loved.
- Take time to celebrate small victories when things go well.

## Primary Care and Family-Centered Dementia Care Models

The Alzheimer’s Association has tested and disseminated family-centered models and tools for primary care diagnosis and management of persons with Alzheimer’s, including guidelines for hospitalization and management of nursing home residents.<sup>10</sup> These collaborative models among physician group practices and Alzheimer’s Association chapter services

## Box 3. Considerations in Determining if a Relative is Safe Living Alone

- 1 Can the person use the telephone, read and send mail, manage their medication and money? Do they drink alcohol?
- 2 Is the person vulnerable to telephone, mail, or in-person fraud, scams, exploitation, neglect?
- 3 Can the person travel safely and at appropriate times outside home without getting lost?
- 4 Can the person maintain personal hygiene? Is the person continent?
- 5 Could the person be at risk for falls or other injuries. Are there guns or power tools, etc. in their home that might pose a risk?
- 6 Is the person at risk in their kitchen? Can they operate a stove safely, store food properly, recognize inedible food, etc.?
- 7 Is the person experiencing any weight loss or sleep disturbances?
- 8 Is discrete surveillance available from neighbors?

could be replicated in North Carolina.<sup>11</sup> North Carolina Alzheimer’s Association chapters also have a national program workshop package available to help families communicate more effectively with physicians around dementia care. Linking health, aging, and social support services makes sense to consumers and health professionals, but the physician or healthcare provider is the lynchpin that makes or breaks seamless care delivery.

## REACH (Resources for Enhancing Alzheimer’s Caregiver Health)

A series of collaborative National Institute on Aging studies provides evidence-based direction for interventions to enhance Alzheimer’s family care capacity and reduce negative consequences for caregiver health.<sup>12</sup> REACH tested interventions in settings ranging from primary care offices to telephone-based to in-home and group settings.

Original interventions targeted challenging behaviors, caregiver distress, delayed nursing home placement, and death. Interventions included cognitive and environmental strategies to reduce negative family appraisals of demands while enhancing the adaptive capacity of family caregivers. Other strategies targeted emotions or affective states of caregivers like depression, anger, and frustration. At six months, the studies reported clinically meaningful, site-specific positive outcomes such as decreases in depression, caregiver strain, and burden (especially among spousal caregivers); and increases in self care, social support, and efficacy in responding to challenging behaviors. When compared to the control group, persons with Alzheimer’s whose caregivers received research interventions had significantly delayed nursing home placement, and their family caregivers suffered significantly less major depression.

REACH studies confirm the efficacy of multi-component interventions matched to individual caregiver risks. Multi-component interventions include a range of treatment modalities (like individual and family counseling, psychoeducational support

# Duke University and Alzheimer's Families

## "The docs back home don't know about this."

North Carolina responded to Alzheimer's families long before national attention focused on the public health and epidemic consequences of memory disorders on individuals, families and communities. Duke's Aging Center began its Alzheimer's Family Support Program in 1979 in response to urgent requests from families of persons with rare early-onset (i.e., before age 65) dementias taking part in the first federally-funded case control studies of Alzheimer's disease led by Duke

University professor of neurology, Dr. Albert Heyman.<sup>1</sup> These families rarely knew of others their age in their communities coping with what was then commonly attributed to "senility or old age." These primarily middle-aged, well-educated couples were eager to meet and learn from each other and from "experts" while the national Alzheimer's Association was initiating its public awareness and support programs.

## From Duke to Mobilizing Communities throughout North Carolina

These research subject families began attending a monthly "support group" at Duke in 1980. They connected with others at the monthly meetings, by writing letters or getting together socially outside of meetings. They urged Duke's Aging Center to publish a newsletter sharing their stories and tips, which the families named *The Caregiver*. Duke's *Caregiver* newsletter is now one of the oldest continuing newsletters for families and professionals caring for persons with Alzheimer's or a related dementia available by free subscription to North Carolina residents. The first-person narratives and tips in this newsletter addressed the isolation of these primarily rural families who lived at a distance from each other and Duke before there was e-mail, the Internet, cell phones or affordable long-distance telephone access. The original Duke support group has continued to meet monthly since 1979, now under the sponsorship of the Eastern North Carolina Alzheimer's Association.

In the early 1980s, North Carolina's Z. Smith Reynolds Foundation and Levi Strauss Foundation funded Duke's Aging Center to mobilize local informal support groups as sources of information and help closer to home. These groups are now part of two North Carolina Alzheimer's Associations sponsoring support groups across the entire state. Original subscribers to *The*

*Caregiver* newsletter became mail survey research subjects for one of the first and most cited studies of Alzheimer's family care in the community.<sup>2</sup>

In 1984, the North Carolina Division of Aging (now the Division of Aging and Adult Services) contracted with Duke's Family Support Program to provide a toll-free telephone and mail clearinghouse for families and professionals caring for persons with memory disorders. The Duke contract covered state-level technical assistance, training, consultation, a newsletter and toll-free individualized telephone assistance. This annually renewed Program contract continues to serve as a state barometer of family needs, preferences, and gaps in health and social support services.

Subsequent studies at Duke and other universities have replicated and expanded original family care research findings. Duke Alzheimer's family care studies moved, along with federally funded cooperative studies, from measuring family stress and burden to interventions to mitigate negative consequences of caregiving on families. North Carolina now benefits from multi-site research findings offering an evidence base for clinically meaningful outcomes of family support strategies aimed at enhanced quality of family and community care for persons with Alzheimer's and related disorders.

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2 George LK, Gwyther LP. Caregiver well-being: A multidimensional examination of family caregivers of demented adults. *The Gerontologist* 1986;26(3):253-259.

groups, self-care programs, and respite care) along with behavioral and skill-building techniques, which are available in standardized reproducible protocols and can be customized to caregiver risk profiles.

## Future Responses to Alzheimer's Family Care

Evidence-based interventions for family caregivers are being translated into intervention protocols and packaged training materials that can be tested or evaluated in community settings. However, there remains a significant need to improve the quality of care in family settings through integration of health and social support services. This seamless, systematic, and more

comprehensive support for families must focus on the vulnerable transition points in Alzheimer's care identified previously in this commentary.

Plans are in place to link this evidence-based research on family caregiver interventions to service delivery systems change in states (like North Carolina) that are participating in the Administration on Aging's Alzheimer's Disease Demonstration Grant to States Program (see Derence article on Project CARE).<sup>13</sup>

While we wait for state policy and service systems change, much can be done to assist physicians and community agencies to collaborate effectively in offering dementia-capable, family-centered care. **NCMJ**

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