



# **Shifting Identities, New Roles**

**UNDERSTANDING CAREGIVERS' NEEDS**

**Research Insights from Mayo Clinic's Center for Innovation Caregiver Initiative:  
Understanding the Experience of Nonpaid Family Caregivers of Individuals  
with Alzheimer's Disease and Cognitive Decline**

**Number 2 in a series of research reports prepared by the  
Healthy Aging and Independent Living (HAIL) program**

**Center for Innovation,  
Mayo Clinic, Rochester, Minn.**

**October 2014**

## About the Center for Innovation

The mission of the Mayo Clinic Center for Innovation (CFI) is to transform the experience and delivery of health care for patients everywhere. The CFI team develops human-centered, groundbreaking solutions and facilitates the application of these discoveries in the practice of medicine.

## Research for the Caregiver Initiative

The Caregiver Initiative is a project designed to support nonpaid caregivers of individuals with cognitive decline. Primary research was conducted with caregivers ranging in age from the mid-20s to the early 90s. Included were both primary and secondary caregivers who were parents, spouses, children and grandchildren of people with Alzheimer's disease, mild cognitive impairment, dementia with Lewy bodies (DLB), frontotemporal degeneration (FTD) and primary progressive aphasia (PPA). The research represented in this paper is based on interviews, observations, home visits and focus groups conducted with 86 caregivers from several states, as well as more than a dozen physicians and other health care providers at Mayo Clinic.

## Introduction

Caregivers play a foundational role for people with dementia. As the illness progresses, it robs people of the ability to make decisions, to organize and plan and to manage the big and small details of daily life. These patients become like “a car without a steering wheel,” says Kurt Hoppe, M.D., medical director of the Rehabilitation Unit at Mayo Clinic.<sup>(1)</sup> It is the caregiver who becomes the steering wheel and navigator.

Because of the tethered relationship between people with dementia and their caregivers, interventions and treatments created for patients will indirectly — and often directly — affect caregivers as well. In turn, optimal patient care requires consideration of caregivers' needs. Empowering caregivers and reducing their burden can help ensure that people with dementia remain safe and as healthy and engaged as possible.

Wives, husbands, partners, friends, sons and daughters don't usually imagine that they might one day be “doing all the driving” for their loved one. The transition into this role unfolds slowly, as both the person with dementia and the caregiver adapt to the shifting terrain of identity, autonomy and expectations. Caregivers may not recognize their new role at first, and some people don't ever identify with the term “caregiver” — rather, they continue to see themselves as a child or spouse or friend. Understanding and defining the varying roles caregivers play, along with other factors that affect individual caregiving situations, can help facilitate successful caregiving.

## Self and family, disrupted

It's hard to overestimate the impact of dementia on individuals and their families and friends. In a word, it's devastating. “Getting the ‘D’ diagnosis is sometimes scarier than getting a cancer diagnosis,” says Ericka Tung, M.D., a geriatrician and primary care physician at Mayo Clinic. “It's like getting the worst possible news.”<sup>(2)</sup>

**“Getting the ‘D’ diagnosis is sometimes scarier than getting a cancer diagnosis. It's like getting the worst possible news.”**

**— Ericka Tung, M.D.,  
Mayo Clinic geriatrician**

Everyone reacts differently to this news, but most people move through a grieving process. The person affected by cognitive impairment and his or her loved ones must grapple with core questions of identity. Does the loss of memory and cognitive ability threaten the existence of self? Is the person with dementia the same person he or she was before the disease? What does this struggle mean for relationships? If the dementia is caused by Alzheimer's disease or another neurodegenerative disorder, progressive changes in the brain lead to a steady decline in cognitive function. As a result, the person's sense

of self and ability to be self-reflective erode over time. People who recognize that they've had a cognitive decline often start to withdraw from activities that previously gave them pleasure, such as playing cards, getting together with family and friends, or participating in their faith organization. Patricia Riestler, R.N., a nurse manager at Charter House, a continuing care retirement community affiliated with Mayo Clinic, notes that some people with dementia resist telling others, even the people closest to them. "It's a way of preserving dignity, not feeling as though they're a burden," she says.<sup>(3)</sup> Along with self-consciousness about cognitive impairment, people may be protecting themselves against the stigma and misconceptions associated with Alzheimer's disease and dementia.

Families also struggle to reconcile their expectations of who the person with dementia is in the present, compared to his or her past identity. It's painful to watch a loved one move from independence to increasing dependence. It's also challenging to understand which tasks the person can still perform and which may be too difficult or complex, especially since the cognitive changes and other symptoms of dementia can be uneven and unpredictable. Having realistic expectations can make the experience easier.<sup>(4)</sup>

### Changing relationship dynamics

The move from independence to dependence prompts profound changes in roles within couples and families — changes influenced by preexisting



relationship dynamics. Partners and spouses may shift into a caregiver-patient or parental role. "If the caregiver was always the one at home taking care of the finances, the medications and the household duties, it's a smoother transition, whereas if those roles

are reversed, that can be more challenging," says Dr. Tung.<sup>(2)</sup>

While the cognitive and memory-based symptoms of dementia tend to get the most attention, psychological and behavioral symptoms can take a heavier

#### A HUSBAND'S STORY<sup>(5)</sup>

Alan has observed that his wife, Lisa, who was just 54 when diagnosed with Alzheimer's disease, no longer wants to go out socially. He wonders if it's because she is afraid she will "look stupid" when she can't finish a thought. One Saturday, the couple planned to go out dancing, but that afternoon Lisa saw Alan working on paperwork related to her disability payment. She became upset and told him she didn't want to go. She also stayed home during the family's Christmas celebration, saying she had a migraine.

Alan and Lisa have been spending a lot of time watching TV, but they recently joined a gym. For Alan, getting exercise and going to church are important ways of coping with stress. He says it's harder to know how to support Lisa. At one of their medical appointments, she had been hoping to learn of a new medication or a change in the diagnosis, but there was no change. "She was very sad and angry when we left the doctor's office," Alan says. "She went right to bed when we got home and stayed there most of the evening." He says she shuts down when she's upset, and he's learned that leaving her alone for a while and coming back later works best for them.

toll on relationships. Behavioral issues such as aggression, agitation and disinhibition disturb relationships and can affect a couple's ability to engage in social activities that they formerly participated in together, such as playing bridge. Sexuality also can be a challenge as roles within a couple change; caregivers may feel less sexual desire as their relationship feels more parental, or they may be uncertain if their partner is capable of consenting to sex.<sup>(2; 4, p265)</sup>

For some couples, one partner's loss of autonomy leaves the other without a crucial source of support, says Riester. "So often couples together make a whole — one may have physical limitations and the other has cognitive limitations, and they help each other and are able to manage."<sup>(3)</sup>

More than half of primary caregivers for people with dementia are children taking care of a parent.<sup>(6)</sup> For children, the role shifts can be equally or even more difficult. "They struggle with that change from

child to taking responsibility for the parent and being accountable and needing to give direction to the parent," says Riester. "They don't want to be disrespectful, overstep their bounds or tell their parent what to do."<sup>(3)</sup>

Some children feel they owe it to their parents to provide caregiving in return for the parents' sacrifices in raising them. Young adult children may give up or change life goals and plans to fulfill their caregiving responsibilities, and may end up feeling as though they've lost their youth.

### Caregiving roles and networks

Being a caregiver isn't a single, static position; rather, it encompasses many different roles and responsibilities that change in response to a fluid experience. Understanding these multiple roles and the factors that affect individual caregiving situations can help in designing services and solutions that benefit people with dementia and their caregivers.

**"The best caregivers are those who learn the limitations of [the] systems but also learn that there are things they can do to make a difference."**

**– Kurtis M. Hoppe, M.D.,  
Mayo Clinic Physical  
Medicine & Rehabilitation**

Caregiving is typically associated with physical care and helping with activities of daily living (ADLs), such as bathing, dressing and toileting. But a caregiver may fulfill several other functions:

- **Anchor.** The primary caregiver keeps the person with dementia grounded. They offer a consistency that enables the person to maintain some orientation in an otherwise dimensionless understanding of the world.
- **Central coordinator and patient advocate.** The primary caregiver becomes the patient's voice and champion, often coordinating care across service areas, care teams, family and friends.
- **Navigator.** People with a chronic, progressive disorder such as dementia lose their problem-solving skills and the ability to negotiate the everyday challenges of life. These functions fall to caregivers, who also must navigate the disparate



## A SON'S STORY<sup>(8)</sup>

Jim has taken the lead in coordinating the care for his elderly mother, Mary, who has dementia. Jim's brother and sister live in a different state and rely on Jim for information about their mother's condition. Until recently, she lived at home with Jim's father, her husband of more than 65 years. Jim hired home helpers to clean the house and provide respite care for Howard, who is in his 90s. Immediate relatives also take turns helping the couple. The family didn't feel comfortable with the hired services and preferred to work with people they knew well. It was also difficult to find impromptu care. "It's like finding a babysitter," Jim says. "It's weird."

Jim retired so that he could spend more time with his parents. It took him awhile to adjust as he struggled to develop a routine and maintain a balance between his own life and the time he devoted to his mother's care. He felt burdened in being the only sibling who lived close enough to spend significant time with their parents. In working with many different service providers, Jim finds the lack of continuity and history with them challenging. He doesn't always trust that they're providing the best care.

systems of a fragmented health care environment. "The best caregivers are those who learn the limitations of those systems but also learn that there are things they can do to make a difference," says Dr. Hoppe.<sup>(1)</sup>

► **Translator.** Caregivers interpret nonverbal or inarticulate verbal cues and communicate the patient's desires across a range of social and health interactions. In turn, caregivers become responsible for translating expert knowledge back into their own experience and updating family and friends.

► **Legal and financial planner.** Caregivers often take responsibility for organizing financial and legal affairs and paying bills.

Other roles may include emotional supporter, resource connector, catalyst (the go-getter who

makes things happen), comedian/entertainer, visitor and expert.

Sometimes one primary caregiver takes on most or all of these roles. This may be due to a lack of support from friends and family members. Just as commonly, however, caregivers are hesitant to ask for help, don't know where to turn for help or aren't sure how to delegate tasks.

Defining caregiving duties in terms of roles may enable strategic approaches to delegating those duties and coordinating care. A network of extended family, friends and paid helpers can act as secondary caregivers with specific roles and responsibilities.

## Social and environmental factors

Many variables work together to influence caregivers' ability to be successful in their roles. Understanding these factors can help in individualizing approaches to care and services and in coordinating an extended care network. Factors that influence the type of care a person or family can provide, as well as the overall caregiving circumstances, include:

► **Relationship to the affected person.** A spouse or partner caregiver has a different experience from a child, grandchild, niece or nephew. The quality of the relationship before the person developed dementia also makes a difference.

► **Social and cultural issues.** Approaches to health, illness, caregiving and social interaction vary significantly among different cultural groups. In some cultures, stigma around dementia presents a barrier to successful caregiving.

Information and resources may be limited due to language or cultural competence issues.

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## Caregivers may or may not have access to social and community resources.

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► **Health.** If the caregiver also has cognitive or physical limitations, the role becomes more challenging.

## A WIFE'S STORY<sup>(7)</sup>

Nancy serves as the primary caregiver for her husband, Bob, who has frontotemporal degeneration and has lost the ability to carry out activities of daily living for himself. Nancy considers caregiving her job, and she takes pride in it. This means making sure Bob is clean, well dressed, well fed and sleeping in a clean bed. Nancy sets out Bob's clothes for him in the morning and makes sure he puts things on in the right order. She gives him a shower and a shave and cleans him up when he experiences incontinence.

Bob tends to pace the house and get into things, and he resists redirection. Nancy finds herself "cussing and swearing" when she has to jump up and go after him many times a day. Once when he left the house, she grabbed his arm, leaving a bruise. She works to control her anger because "he doesn't deserve that."

Still, Nancy says she feels like a robot: "Do this, don't do this, sit here, come here, sit down." She worries that while she's protecting Bob, she's also taking something away or not letting him be himself. She says she doesn't feel like she's taking care of her husband — rather, she's providing care for a person who is living with her. She's exhausted from caregiving. "I deserve a life," Nancy says.

➤ **Gender.** About 65 percent of caregivers for people with dementia are women.<sup>(6, p30)</sup> Men and women may grieve and seek support differently — although such differences aren't universal.

➤ **Age.** Caregiving can be especially challenging for elderly adults, who likely have their own health issues. About 30 percent of adult caregivers for parents with dementia have minor children living with them.<sup>(6, p31)</sup> These "sandwich generation" caregivers are at risk for burnout, depression and anxiety. Young adults who become caregivers to parents or grandparents may not have daily interaction with the care recipient, which can make it difficult to get an accurate picture of the

older person's condition.

➤ **Resources.** Limited community resources and tightening of eligibility for Medicaid has created a vulnerable population of patients and caregivers, says Dr. Hoppe. "If you take away all the health care dollars, the economic deprivation that occurs because of sickness and injury does not go away," he notes. "You just push it onto someone else. Usually it's the caregivers and families, who are ill-equipped or don't have the prowess necessary to deal with socioeconomic decline. Disabilities are family affairs."<sup>(1)</sup> In addition to financial resources, caregivers may or may not have access to social and community resources, such

as friends, family members, faith communities and private-public partnerships such as ACT on Alzheimer's, a volunteer-driven effort to prepare communities for the impact of dementia.

➤ **Location.** Nearly 15 percent of caregivers for people with Alzheimer's disease live an hour or more away from their loved ones.<sup>(9)</sup> About 1 in 5 of these is a primary caregiver.<sup>(9)</sup> Long-distance caregivers often become care coordinators, helping to locate and monitor the ill person's care and services.

## Fostering success in caregiving

Just as caregiving roles and circumstances are multiple and varied, caregivers' and care recipients' experiences and outcomes also range widely. At one end of the spectrum, burned-out caregivers are at risk for abuse or neglect of the person with dementia. On the other side, many caregivers maintain tender, loving relationships with people who have dementia and strive to preserve their dignity and autonomy as much as possible.

A key component of successful caregiving is the ability to safely meet the needs of the person with dementia. Successful caregiving also means preserving the caregiver's own health and well-being. Success isn't a fixed point but lies on a continuum that includes moments of failure, setbacks, disability and death — all of which are part of the journey of living with dementia. "It's a fluid experience," says Riester. "Caregivers have new things to cope with as cognitive impairment or dementia progresses."<sup>(3)</sup>

Another crucial resource for caregivers is their own view

of their role and the meaning they derive from it. Attitude, perspective, optimism, faith and spiritual connections all contribute to successful caregiving. “In medicine we don’t spend a lot of time talking about those facets, because they’re harder to measure,” notes Dr. Tung.<sup>(2)</sup> But, she says, a caregiver’s outlook can help him or her stay resilient through the long process of caring for someone with dementia.

“One of the things I see in successful caregivers in couples is that they really try and engage their loved one as best they can,” says Dr. Tung. “Maybe their loved one can’t participate as much, but they still bring them to bridge. They still bring them to the grocery store, even though their loved one can’t help and it might take longer.”

Riester agrees. “The level of devotion is remarkable. That’s why we become concerned about caregivers, because they put their partner’s needs ahead of their own.”<sup>(3)</sup>

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## Successful caregiving also means preserving the caregiver’s own health and well-being.

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– Ericka E. Tung, M.D.

### PREVENTING ABUSE

Supporting caregivers for people with dementia is crucial in helping to prevent abuse of this vulnerable population. When caregivers are exhausted and burned out, they’re more likely to mistreat the person in their care. Early in the course of cognitive impairment, people are at risk of financial exploitation, says Dr. Tung.<sup>(2)</sup> As the disease progresses, behavioral disturbances and physical aggression become more common, and the risk for physical abuse from caregivers increases. In the later stages of the illness, people with dementia may be bedbound and at risk for neglect.

“A healthy balance between being able to protect people with dementia and optimize their care, and bolstering caregivers, is really important so we can prevent those types of abuses,” says Dr. Tung.<sup>(2)</sup>

## Opportunities to help caregivers

These research insights suggest strategies that can help support successful caregiving.

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# 1

### **Integrate the caregiver into planning from the beginning, and provide a single point of reference for managing all care needs for both the patient and caregiver.**

Acknowledge the tethered relationship between people with dementia and their caregivers by involving the primary caregiver upfront in care planning and decision-making. Early coordination allows patients to clarify their desires for care in later stages of the disease, such as planning for sedation in case of violence so they won't harm their caregiver. When care involves multiple service providers, it's helpful to identify a single contact person or coach who can work with caregivers for the duration of the disease.

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# 2

### **Individualize approaches based on the caregiver's role and circumstances.**

Use personas (characters that represent different customer, client or user types) or other tools to design personalized interventions that take into account a caregiver's role, relationship to the care recipient, location, culture and other variables. Cultural competence training may be needed for medical and other care providers.

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# 3

### **Facilitate communication.**

Provide a single, clear, nonclinical care plan that can be regularly updated and easily shared with multiple caregivers across different locations. Ideally, the nonclinical care plan would be integrated with the clinical electronic record.

Address barriers to communication, such as language or health literacy. Because cognitive, physical, behavioral and other symptoms change as dementia progresses, caregivers continually need new information, guidance and education throughout the course of the disease. Frequent communication is key.

Lower-touch communication tools may also promote communication and engagement between patients and caregivers and their extended networks. "Social media can be helpful," says Dr. Hoppe. "It can provide patients and families with information and problem-solving abilities."<sup>(1)</sup>

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**As dementia progresses, caregivers continually need new information, guidance and education.**

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## 4

### **Frame caregiving as a job with specific duties that can be delegated.**

Caregivers fulfill many roles and responsibilities. Breaking these down, akin to a job description, can make it easier to delegate tasks to other nonpaid and paid caregivers based on areas of strength and expertise.

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## 5

### **Acknowledge a caregiver's identification with the role.**

For many caregivers, caregiving becomes their identity and a source of self-worth. "Their whole schedule, life and worldview revolve around their [loved one]," Dr. Tung says. The death of the person with dementia may trigger a loss of identity as well as a grieving process. At this point, caregivers may need to reinvent themselves or recover a sense of who they are beyond a caregiver.

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## 6

### **Help caregivers take advantage of available resources.**

Even caregivers who are coping well need breaks to rejuvenate, but they often don't have time to seek out resources. Health care professionals can help unburden caregivers by connecting them with resources such as home health care, respite care and adult day programs. However, because health care providers also face time constraints, linking these resources to practice tools such as electronic health records could make this process easier.

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## 7

### **Advocate for better public and private support systems.**

Many communities, especially in rural areas, lack resources for people living with dementia and their caregivers. As the population ages, fewer potential caregivers are available for each person with dementia<sup>(10)</sup>. Legislative and community efforts are needed to increase support for this growing population.

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## 8

### **Focus on resilience and meaning.**

Practices that help caregivers find meaning in their role and approach it with optimism, patience and faith can help them stay the course. Such practices might include prayer, meditation, yoga, counseling and participation in faith and religious services and activities. Caregivers also need an outlet to express feelings of anger and loss. Caregivers carry an additional burden because they don't feel they can complain.

## Bolstering hope

Caregivers and the people they care for remain tethered in a changing relationship through the shifting, nonlinear, often unpredictable journey through dementia. The experience entails a constant renegotiating of roles and identities in the face of ongoing challenges and losses. Because of the stigma associated with cognitive impairment, friends and family may disappear, leaving caregivers feeling isolated and alienated on top of their increased burden of responsibilities. For these reasons, support for caregivers is a critical aspect of ensuring optimal care for people with dementia and preventing harm to patients and caregivers.

Despite the difficulties, caregivers often discover unexpected reserves of strength and humor. One caregiver says that it took her awhile to “accept what is,” but getting to that point has made life easier. She likens the ups and downs of living with her husband’s dementia to the ocean tide going in and out.<sup>(1)</sup> Caregivers who successfully navigate these waters offer hope for others in the same situation. Bolstering caregiver resources can help more families provide the best care they can without sacrificing their own health and wellness.

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