Predictable Chaos

CAREGIVING AND THE DEMENTIA LIFE CYCLE

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 1 in a series of research reports prepared for the Healthy Aging and Independent Living (HAIL) Consortium.

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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. The center uses a patient-centered focus to transform the experience and delivery of health care for patients everywhere. The CFI team develops 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 progressive primary 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
Every family caring for someone with dementia has stories to tell. The wife who couldn’t find her car at the mall. The husband who left the house early in the day to run a quick errand and didn’t return until midafternoon, after driving more than 150 miles. A mother who believes her adult daughter is her student. The grandfather discovered face down in the mud in a cornfield.

Every person’s journey through dementia is different. Yet these stories sound familiar, because the process of cognitive decline, whether caused by Alzheimer’s disease, frontotemporal degeneration, Parkinson’s disease or another neurodegenerative disorder, produces common symptoms and behavioral changes — which often lead to predictable crises. Despite its variable nature and timeline, dementia contains some overarching phases. In turn, caregiving follows a trajectory tied to phases in the dementia life cycle.

Understanding these phases can help in designing products and services that reflect and are relevant to particular moments along the journey — services that meet caregivers’ needs can help them feel less alone and overwhelmed.

One caregiver who participated in a Mayo Clinic support group said it was helpful to hear that her experience was normal. “I come unglued, but it’s just part of the process,” she said. (1)

Cognition isn’t an either-or proposition: normal or abnormal. Rather, a person’s cognitive status may fall somewhere along a spectrum from normal function, where cognitive skills are intact, to dementia, where disease has severely disrupted cognitive skills. Between these extremes lie many functional levels, including cognitive changes that occur as part of typical aging. (2, pp34–37)

How well people retain their cognitive skills as they get older varies widely. Misplacing keys or forgetting a name at times is normal. But some changes that happen later in life indicate more serious cognitive decline. (2, pp34–37)
Normal vs. abnormal aging (2, pp43-44; 3)
According to Mayo Clinic neuropsychologist Julie Fields, Ph.D., subtle changes in memory and other cognitive functions may begin around age 50.

Normal aging involves:
- Slowed mental processing
- Slowed decision-making ability
- Reduced amount of information that can be processed at the same time
- Less flexibility in thinking
- Occasional forgetfulness, especially people’s names

Indicators of abnormal aging include:
- Difficulty keeping track of what happens each day
- Lack of interest in usual activities
- Change in routine daily activities
- Trouble processing information, especially new information
- Frequent memory problems and periods of confusion
- Symptoms that worsen over time

Beyond the changes of typical aging is mild cognitive impairment (MCI), also referred to as pre-dementia. Mild cognitive impairment isn’t as severe as dementia and doesn’t significantly affect a person’s daily life. People with MCI face a higher risk of developing dementia, but don’t inevitably do so.

Aging and cognitive change
This graph illustrates the different paths that cognition may take as people age. The vertical axis indicates the cognitive spectrum, with good cognition at the top of the axis and poor or impaired cognition at the bottom of the axis. The horizontal axis indicates years of age. Cognition levels range across the spectrum.
**What is dementia?** (2, pp37–40; 3–5)
Dementia occurs when at least two different cognitive functions, including memory,
decline substantially. Signs and symptoms of dementia include memory loss,
difficulty communicating, inability to learn new information, inability to reason,
difficulty with planning and organizing, personality changes, inappropriate
behavior, paranoia, agitation, disorientation, confusion and hallucinations.

Dementia is not a disease but a syndrome — a collection of signs and symptoms
caused by an underlying disease, most commonly Alzheimer’s disease. Other
diseases that cause dementia include frontotemporal degeneration (FTD), dementia
with Lewy bodies (DLB), Parkinson’s disease, primary progressive aphasia, vascular
disorders and Huntington’s disease. Dementia or dementia-like symptoms can also
stem from treatable health problems such as infections, depression, metabolic or
endocrine diseases, alcoholism or other substance abuse, and brain tumors.

If dementia is caused by a neurodegenerative disorder such as Alzheimer’s
disease, the changes in the brain are progressive, resulting in a steady,
dramatic decline in cognitive function. On average, people age 65 and older
with Alzheimer’s disease live for four to eight years after being diagnosed,
but some people live with dementia for a decade or longer. (5, p27)

Traditionally, disease progression is tracked clinically, through tests and imaging.
For dementia, progression is seen most clearly through behavioral symptoms.
Many different types of dementia share similar behavioral symptoms. Although
the time course of the disease (“when”) isn’t predictable, the key points in the
journey (“what”) are. And these key points correspond to particular phases
and challenges in living with and caring for someone with dementia.

“People get hung up on stages. It’s really just a continuum. People experience
different hallmarks at different points.”
— Glenn Smith, Ph.D.
Mayo Clinic neuropsychologist (6)

**Losing Bette: A Caregiver’s Perspective** (6)
When Duane looks back on the time before his wife, Bette, was diagnosed with
eye-onset Alzheimer’s disease, he realizes that his role in their relationship
had begun to shift long before her symptoms prompted a visit to the doctor.
Two years earlier, she had lost all interest in cooking, Duane recalls. “But
not in eating,” he says. “I became the chief cook and bottle washer.” (9)
Over the next couple of years, he noticed that she would forget to write things in her checkbook, and her handwriting had deteriorated. One day, Duane saw Bette with a telephone directory. She was looking up the number for her close friend — a woman she talked to almost every day. Duane knew something was wrong. “Bette was the kind of person who, if she called you once, she knew your number,” he says.

When Bette was first diagnosed, she didn’t want anyone to know. But soon she started telling friends, because she wanted them to understand the changes they might see in her. Unfortunately, Duane says, many of their friends disappeared. “People we’d socialized with for years were just gone. Her friends abandoned her,” he says. “She’d leave a message and they’d never call back. That was wearing on her.”

After the initial diagnosis, Duane and Bette saw a neurologist who did further testing and changed the diagnosis to dementia with Lewy bodies. Duane and Bette also joined a support group.

With his added responsibilities at home, Duane found his patience tested. One day he snapped at Bette. She responded, “I did not choose to have this disease.” One of the support group facilitators, Glenn Smith, Ph.D., a professor of psychology at Mayo Clinic and expert in dementia, told Duane, “You have the right to be angry, but you can’t be angry with Bette. You have to be angry with the disease.”

— Glenn Smith, Ph.D.
Mayo Clinic neuropsychologist

After that, Duane changed his attitude. “It’s made me a more patient person with family and friends,” he says.

Although Duane and Bette belonged to a church, he eventually stopped taking her. It was difficult for her to get from the car into the church, and she wasn’t able to focus on the sermon. As Bette “progressed down the hill,” as Duane calls it, he realized that he could no longer leave her alone in the house. Then, one evening — Duane remembers the exact date in December three years after her diagnosis — Bette looked at him over the supper table and asked, “Why isn’t Duane eating with us?”

Caregivers: A large and growing population

Caregivers are defined as nonpaid persons who provide in-home care to a patient. They are spouses, partners, children, parents and friends. In the United States, 65 million people are serving as caregivers. Of these, nearly 25 percent are caring for people with Alzheimer’s disease or another type of dementia. These numbers are expected to grow significantly as the population ages. Alzheimer’s and dementia diagnoses are expected to double by 2030.

At the same time, the number of people aged 45 to 64 who can provide care for older family members is unlikely to keep pace with future demand, according to AARP. As the baby boomers age, the ratio of potential family caregivers to care recipients will fall from 7 to 1 in 2010 to 4 to 1 in 2030.
“No matter how much you know that it’s coming, it’s still a shock,” Duane says.

Over time, Bette, once someone who could “talk your ear off,” became less and less communicative. When she became unresponsive, Duane moved her to a skilled care facility, where she died just 15 days later.

Losing Bette has created a vacuum in Duane’s life. Although caregiving was challenging, he found it rewarding, and he always knew his wife was “still in there,” despite the disease. “I think of Bette every day,” he says.

The caregiving journey

As a person with dementia gradually declines, moving from normal behavior and independence to abnormal behavior and total dependence, the caregiver also is on a journey. It may be unrecognized at first, unwelcome at times and nearly always challenging. Each new manifestation of the illness may be marked by a loss, such as the ability to write, remember phone numbers or hold conversations. These losses often lead to emotional and practical crises and become increasingly serious throughout the disease progression.

While every caregiver’s experience is different, many go through these phases:

**Figuring out there’s a problem**

Individuals and families may not recognize dementia for many years, passing signs and symptoms off as the person “getting old.” They may notice little things, like the person repeating himself more or Bette’s deteriorating handwriting. Many caregivers report a turning point or moment of shock when they realize that something is really wrong. Sometimes one person suspects a problem but has trouble convincing others in the family that something is wrong. With early-onset dementia, says neuropsychologist Glenn Smith, Ph.D., symptoms might lead to marital challenges. “The presumption is that it’s a personality change rather than a brain change,” he notes. (6)
**Getting a diagnosis**

At this point, the family may consult a family physician and may be referred to a neurologist. Even within the medical community, however, dementia isn’t well understood and is often hard to diagnose. Early signs can be mistaken for symptoms of other diseases, such as depression, anxiety or sleep disorders. A lack of reliable diagnostic tools or tests to identify disease processes in the brain means that diagnosis is often a matter of excluding potential causes.

**Becoming a caregiver**

Often it’s not clear exactly when caregivers become caregivers. Duane took on cooking duties long before he realized Bette had dementia. For others, receiving a diagnosis brings a conscious decision to move into a caregiver role. Once an individual becomes the primary caregiver, he or she typically serves as point person, patient advocate and problem solver. One woman noted that she always has her husband’s needs in mind and that caregiving means “living two lives in one body, mind and soul.” (10) While some primary caregivers shoulder the entire burden, many draw support from an extended network of secondary caregivers.

**Telling others**

Deciding whom to tell and when can be difficult. The person with dementia may feel “under the microscope” as people watch for signs of illness. Caregivers may feel torn between protecting the loved one’s privacy and sharing parts of their emotional roller coaster. In telling others about the dementia, caregivers have an opportunity to identify people in their lives who may be able to offer support, including family, friends, neighbors and co-workers.

**Grieving … and grieving again**

A hallmark of living with a loved one with dementia is the experience of “ambiguous loss”: losing the person to the disease before the disease takes his or her life. This is a long, drawn-out process, marked by a series of smaller losses, such as memories, hobbies, abilities and personality traits. In a repetitive cycle of loss and grieving, caregivers must let go again and again. One woman told about how her husband woke up in an especially good mood after having a dream that he was out fishing with his buddies. She felt sad and sorry that he couldn’t do the things he once did. (11)

**Living in a shrinking world**

Caregivers are at risk of becoming isolated after a loved one is diagnosed with dementia. Even when there’s an extended network of caregivers, many friends and family fall away as the person with dementia becomes less capable of participating in social activities and more disturbed by changes in his or her environment. Acquaintances, friends and family are often misinformed about and fearful of dementia. Those who try to stay in touch often struggle with not knowing what to do, how to help or how to handle the situation overall. Caregivers, for their part, often don’t have time to commit to social obligations and reciprocal relationships.

**Handling ADLs**

Activities of daily living (ADLs) are routine tasks that people do to stay healthy and take care of themselves. Early in the disease process, a person with dementia may still be able to accomplish most of these activities. In time, however, cognitive losses and a loss of fine motor skills result in the need for a caregiver’s help. ADLs include: (2, 289–300)

- Bathing
- Grooming, including hair care, shaving and trimming nails
- Brushing teeth
- Dressing
- Eating
- Toileting

In practice, these tasks can be emotionally and physically exhausting. One woman felt angry that she had to clean urine from the floor of her husband’s room every morning and then wash him up in the shower. One morning, she found herself using “every swear word in the book” after her husband defecated in the shower; as she was cleaning up, the toilet plugged. As she worked to unplug it, her husband went back into the bedroom and urinated on the treadmill. (13)
Managing increasing responsibilities
In the early stages of dementia, caregivers often place most of their effort into normalizing the situation for the care recipient. Over time, the care recipient’s needs intensify, and the caregiver’s life centers on coordinating and managing care, including activities of daily living, such as bathing and dressing. It’s a 24/7 job. One woman notes, “Your life isn’t yours.” (12)

Repurposing the home environment
The home environment reflects changes in disease progression, coping strategies and quality of life. The caregiver may make changes to the physical environment to adapt to the changing needs and behaviors of the care recipient. Some people label everything in the house or use pictures to show the purpose of items. One wife kept all the power tools on the dining room table because that’s where her husband looked for them. Rooms may lose their traditional functions to accommodate shifting needs and routines. The care recipient’s bed may be set up in the living room or family room, for example, to be closer to the kitchen and bathroom or to avoid needing the stairs.

Burning out
Further into the disease journey, the care recipient becomes totally dependent on the primary caregiver. Challenging behaviors, physical aggression and emotional outbursts are common and can cause extra strain on the caregiver. Often care recipients are unable to recognize their own need for care and may fight the caregiver. The lack of a reciprocal relationship can make caregivers feel lonely even though they are rarely alone. They become exhausted and may not be sleeping well or attending to their own needs. Triggers for burnout include a sense of being overwhelmed with anxiety, anger, fear or guilt.

Acknowledging the need for help
Often caregivers try to maintain an image of strength or stoicism. They may feel as though they would be failing if they accepted help. They may not know where to turn or how to ask for help. Most of the time, true respite can only be provided when the caregiver and person with dementia both know and trust the individual who steps in. In order to accept help, the caregiver must let go of the idea that he or she is the only one who can do the job, and also must recognize the importance of self-care. A common moment of insight and acceptance is the thought: “What would happen to this person if I wasn’t there?”

Doing all the driving: difficult milestones
As dementia progresses, caregiving may reach a new level of intensity when the affected person:
- Can no longer drive
- Can’t take medications according to the directions
- Can no longer be left alone because of safety concerns, such as wandering, leaving the stove on or falling
- Shadows or “puppy dogs” a caregiver, so the caregiver is never out of sight
- Struggles with communication, sight, hearing or mobility, which may lead to challenging behaviors or emotional outbursts
- Becomes incontinent
- No longer recognizes the caregivers

Diagnosis
No more driving
Can’t be alone
Move to nursing home
Death

- Noticing small things
- Moment of shock
- Telling others
- Strange discoveries
- Staying home
- No more walks
- Outbursts
- Forgetting people
- Can’t talk on the phone
- Little sleep
- Feeling empty
- Unresponsive
- Alone
Arranging for more care
If caregiving becomes too burdensome, caregivers may arrange for home health care or decide to move the person to an assisted living or skilled nursing facility. In addition to the logistical and financial challenges of finding a care facility, caregivers often struggle with guilt about the decision. Once the move is made, the caregiver’s burden isn’t necessarily removed. The focus shifts to maintaining the quality and level of care the receiver had been getting at home. In addition, the move represents yet another loss. “You miss the companionship and think about them every day,” said one caregiver. (15)

Navigating the end of the journey
Dementia eventually leads to death. When the person passes away, the caregiver experiences the final of the series of losses. Each person’s grieving process is unique, based on the relationship, level of emotional support, culture and circumstances. Caregivers need to transition to a new identity and role and perhaps find a new sense of purpose in life.

Opportunities to help caregivers
Effective, appropriate services, technologies and products will support caregivers at the points they need them most within the dementia life cycle. Consider these goals for caregiver interventions and tools:

1) Normalize the process
The experience of living with dementia often involves a series of crises that can feel chaotic and unpredictable.

One way to provide support is to give caregivers the sense that their experiences and feelings are normal and that they’re doing the right thing.

It’s also helpful for caregivers to understand how behaviors in a person with dementia might reflect needs, disease progression and underlying medical issues.

2) Encourage early diagnosis and planning
Helping people understand the differences between typical and abnormal aging, as well as signs and symptoms of cognitive decline, can encourage earlier clinical diagnosis. Without a diagnosis, families may be reluctant to prepare for possible changes ahead. When a diagnosis is made, people understand that the signs and symptoms stem from a disease process and look to the medical community for guidance. Another opportunity for intervention is to encourage care planning even without a diagnosis, when changes in behavior become apparent.

Caregivers at Risk
Caregivers may support their loved ones for many years, handling a tremendous amount of stress — and often neglecting their own needs. As a result, many caregivers struggle with their own health challenges: (14)

- Caregivers of people with dementia face a greater risk of developing high blood pressure, coronary heart disease and stroke.
- Caregivers are more likely to develop dementia themselves compared to those who aren’t caregivers.
- Spousal caregivers of people with dementia often die before the caregiving recipient dies.
3) **Provide guidance for planning ahead**
One of the biggest challenges of caring for people with dementia is not knowing how long the current situation will last, what will happen next or how to plan ahead. As a result, caregiving is often reactive, and many caregivers later express regret about their hesitation in taking certain steps and making decisions.

Professional collaboration and guidance may provide the confidence and knowledge to enable proactive care planning. The earlier plans are created for certain key points in the journey, the better. Having a plan ahead of time helps create space for processing the emotional side of events as they happen. It would be especially valuable to offer a holistic plan that addresses the needs of both caregivers and care recipients across many resource domains: legal, financial, social, clinical, physical, emotional, spiritual, technological.

4) **Emphasize the importance of self-care**
It’s important to encourage caregivers to take care of themselves early in the journey, before they become physically and emotionally exhausted, burned out or ill themselves. Caregivers need respite, but even if it’s offered, many caregivers don’t take advantage of it. Part of the challenge is to help caregivers accept that by caring for themselves, they’re actually caring for their loved one. How can they strike a balance between their (unpaid) caregiving job and their own health and well-being? What incentives can be offered to help them find that balance and focus on themselves before the next crisis occurs?

5) **Link support and tools to specific stages of the journey**
Personalized, relevant support will meet the particular needs of the different phases of the caregiving journey, not just the beginning or end. For example, grief support typically follows the death of a loved one, but caregivers deal with grief as they cope with multiple losses throughout the progression of dementia. This suggests a need to shift traditional models of grief support. Home assessments and technology can help support caregivers in optimizing their physical environment to adapt to the care recipient’s changing needs. Long-distance caregivers can use technology to provide support remotely for care recipients who live alone, thus extending their ability to live independently.

6) **Connect caregivers with others**
One of the most important means of supporting caregivers is to help them connect with others who are in or have been on the same journey. Hearing others’ stories helps normalize the caregiver’s experience and reduces the sense of isolation they feel. Talking with someone whose loved one is at a more advanced place within the dementia life cycle can show the path forward, while sharing one’s own experience helps others benefit from it and can provide a sense of purpose.

7) **Recognize the individual experience within the common journey**
A common saying in the Alzheimer’s community is, “If you’ve met one person with Alzheimer’s, you’ve met one person with Alzheimer’s.” Even while mapping common signposts along the caregiving journey, it’s important to remember that solutions may not be appropriate in every situation. Individuals and families require distinctive care plans and support options.
References

Notes

1. Interview conducted by CFI. (File “Exit interview Linda” and dated 2/23/2012: \mfad.mfroot.org\rchdept\CenterForInnovation\Dept\PROJECTS\Future Works\Caregivers\Research\CaregiversFinals\Thompson, Gerise\Exit Interviews.)


10. Interview conducted by CFI. (File “Roehl notes” and dated 2/21/2012: \mfad.mfroot.org\rchdept\CenterForInnovation\Dept\PROJECTS\Future Works\Caregivers\Research\CaregiversFinals\Thompson, Gerise\Caregiver Notes.)

11. Interview conducted by CFI. (File “Cherney notes” and dated 2/6/2012: \mfad.mfroot.org\rchdept\CenterForInnovation\Dept\PROJECTS\Future Works\Caregivers\Research\CaregiversFinals\Thompson, Gerise\Caregiver Notes.)

12. Interview conducted by CFI. (File “Black notes” and dated 2/21/2012: \mfad.mfroot.org\rchdept\CenterForInnovation\Dept\PROJECTS\Future Works\Caregivers\Research\CaregiversFinals\Thompson, Gerise\Caregiver Notes.)

13. Interview conducted by CFI. (File “White notes” and dated 2/6/2012: \mfad.mfroot.org\rchdept\CenterForInnovation\Dept\PROJECTS\Future Works\Caregivers\Research\CaregiversFinals\Thompson, Gerise\Caregiver Notes.)

14. Interview conducted by CFI. (Leslie Ruckman notes from interview on June 14, 2011.)

Resources

Organizations

AARP Caregiving Resource Center
www.aarp.org/home-family/caregiving/
Alzheimer’s Association
www.alz.org

Alzheimer’s Disease Education and Referral (ADEAR) Center
www.nia.nih.gov/alzheimers

Family Caregiver Alliance
www.caregiver.org
Lewy Body Dementia Association
www.lbda.org

Mayo Clinic Alzheimer’s Disease Research Center
http://www.mayo.edu/research/centers-programs/alzheimers-disease-research-center/overview

National Institute of Neurological Disorders and Stroke
http://www.ninds.nih.gov

National Institute on Aging
http://www.nia.nih.gov

Books


Movies
Away from Her
http://www.imdb.com/title/tt0491747

Iris
http://www.imdb.com/title/tt0280778

Nine for IX: “Pat XO”

The Savages
http://www.imdb.com/title/tt0775529