



Gail Sheehy and Clay Felker's wedding,
with guest, David Frost (left).

The Most Perplexing Passage

In her new book, *Passages in Caregiving: Turning Chaos into Confidence*, bestselling author Gail Sheehy offers a first-hand look at the challenges and opportunities faced by those who care for others.

When *Passages* first hit the bestseller lists back in 1976, author Gail Sheehy became known as an expert on what she referred to as the predictable phases of adult life. She followed this smash hit with several other books that guided men and women through additional issues commonly encountered by members of the Boomer generation. But even Gail Sheehy failed to predict the role that occupied her for 17 years of her own adulthood: serving as caregiver for her ailing spouse.

In her latest book, *Passages in Caregiving*, Sheehy poignantly details her experiences caring for her husband, renowned magazine editor and publisher Clay Felker, from the day of his initial cancer diagnosis in 1991 until the day he passed away in 2008. Using her personal narrative as a backdrop, she presents a comprehensive overview of the various steps most people take during the caregiving odyssey. The book is packed with advice from medical, legal and elder-care professionals along with practical tips from many caregivers whose true stories are woven throughout the pages.

“We should all be prepared for the caregiving role, but it’s built into our nature to fear and deny the ideas of decline and death so we don’t see it until it hits us in the face,” Sheehy says. “Caregiving is very much on the continuum of predictable passages in our lives.”

Finding Yourself in the Labyrinth

In the book, Sheehy uses a labyrinth metaphor to describe the confusing, chaotic journey typically traveled by caregivers. She refers to eight specific “turnings” that caregivers take and devotes an individual chapter to each of them. While *Passages in Caregiving* is designed to support all categories of caregivers, it contains plenty of information that applies to the unique demands placed on those caring for individuals with Alzheimer’s disease (AD) or other forms of memory loss.

Here, Sheehy describes the eight turnings and how they might apply to the AD caregiver:

- 1. Shock and Mobilization.** Unlike other life-changing diagnoses, memory loss involves a more gradual transition from health to illness. “The passage into dementia is a creeping crisis,” says Sheehy. “Most caregivers I interviewed who were dealing with Alzheimer’s realized it had been evident for quite some time before they acknowledged it. And it would be even more time before they could get on the same page with their loved ones about needing to address it.”
- 2. The New Normal.** Embracing the realities of memory loss requires adjusting expectations and preparing for change. “Sometimes dealing with illness is a sprint and other times it’s a marathon,” explains Sheehy. “In the case of Alzheimer’s, it’s always a marathon because of the long onset and long period of decline.”
- 3. Boomerang.** In this chapter, Sheehy discusses what happens when things change, either due to disease recurrence or to a sudden shift in caregiving duties. For AD families, the boomerang often hits when the original caregiver (such as a spouse) becomes incapacitated and responsibilities fall instantly on other relatives (such as adult children). Sheehy offers tips on how to deal with these urgent adjustments to the “circle of care.”
- 4. Playing God.** It’s easy for AD caregivers to assume the all-knowing role in their loved ones’ lives because they have to monitor so many levels of change. “There are physical, emotional, spiritual and social changes

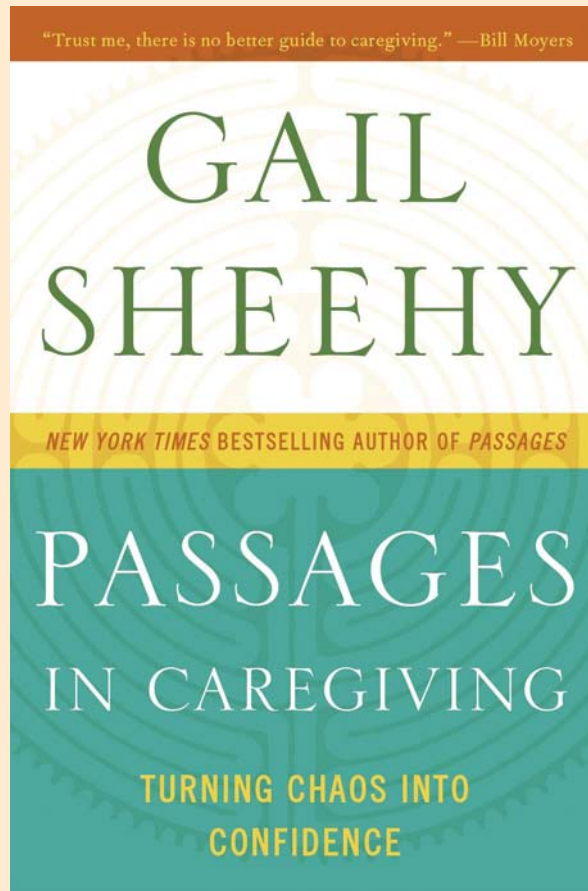
to deal with, along with denial and fear,” Sheehy warns. Caregivers, she says, must remember not to lose themselves to their attempts at controlling the uncontrollable. She writes of a man who tried to deny the seriousness of his wife’s AD until he became little more than her shadow. “It became apparent to him that he wasn’t God and that he wasn’t making it better by having no life of his own. He gradually gave himself permission to resume his former activities,” she reports.

5. “I Can’t Do This Anymore!”

Here, Sheehy acknowledges the frustration that most caregivers experience—sometimes numerous times—along the way. For loved ones of AD sufferers, this stage is excruciatingly common. “This isn’t a startling phase for people dealing with memory loss; they may come to this place several times,” she notes. “It becomes repetitive, as do the needs and demands of the Alzheimer’s patient.”

6. Coming Back. This turning must be interpreted differently by AD caregivers, since there is little to no possibility that the individual will return to his or her former place of cognitive health. “Here, it’s clearer that caregivers have to let go and detach while still being present and compassionate,” Sheehy advises. “When caregivers become more and more attached to the point where there is very little separation between themselves and the ones they care for, it’s a recipe for going down with the patient.”

7. The In-Between Stage. Many caregivers and patients facing life-threatening conditions must make important decisions about whether to pursue treatments—both medical and palliative—in the latter stages of illness. Families dealing with AD approach this



Gail Sheehy's latest book, *Passages in Caregiving*.

turning from a slightly different perspective, Sheehy says, since there is no known cure for Alzheimer’s dementia. Accordingly, there is virtually no conflict for AD caregivers about how to manage palliative treatment at this stage other than to continue to provide as much physical and emotional comfort as possible.

8. The Long Goodbye.

All caregivers want answers to the burning questions surrounding time and prognosis. “The long goodbye is often very long with an Alzheimer’s patient,” Sheehy points out. “The caregiver in this case has absolutely zero control over how long and very little control over what he or she can do to shape the situation. The best idea is to enjoy communication while it’s still possible before the final stages of the disease set in.”

Understanding Dependence

Although her husband never suffered from substantial cognitive impairment, Sheehy watched as his physical limitations began to affect him in other ways. “As Clay lost some of his robust physical capacities, he also lost some mental capacities,” she recalls. Several years before he died, he reluctantly admitted to her that he could no longer read. “He’d been reading all of his life; it was the single activity he spent doing more than anything else,” she says. “It was a shameful, terrifying thing to him to lose that ability, but the effort of concentrating fatigued and frustrated him in much the same way it does for Alzheimer’s patients.”

That, Sheehy says, is when she first realized the connections among mental, emotional and physical dependence. “With Alzheimer’s patients, caregivers need to find ways to keep them connected to life and to action as their physical mobility and cognitive abilities decrease,” she says.

Caregiving for Caregivers

Caregivers must also remember to treat themselves well, Sheehy asserts. Throughout the book, she reminds her



Gail, her grandson, Clay, and daughter Maura, in 2008.

readers that “caregivers need caregivers.” For those taking care of individuals with memory loss, this is especially true. “Alzheimer’s caregivers must connect as often as possible with the rational thinking world,” she says. “They need that contrast to the diminishing faculties of their loved ones.” Seek out old friends, extended family members or companions for activities, she advises. The point is not to get buried inside the world of memory loss. “Counteract the frustration of being with a person with whom you used to have full communication,” she urges.

During the years of her husband’s illness, Gail Sheehy learned a lot about taking care of a loved one. In the years since his death, she has learned a bit about taking care of

herself. “I’m trying to learn how to be more concentrated on self-care,” she says. “Not selfishness, but self-care, which are two very different things.”

Sheehy writes in *Passages in Caregiving* that a primary goal for the book is “to redefine the role of caregiver from solitary sacrificial lamb, shouldering the whole burden alone, to compassionate coach who learns how to attract and assemble a circle of care.” The good people who tend to individuals with Alzheimer’s disease and other forms of memory loss will likely recognize themselves in Sheehy’s characterization. More importantly, they will find empathy, community and direction in the pages of her book—one that can shed light on an often dim passage. ■