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Helping someone live until they die

Maureen Daly | Dec. 1, 2010

PASSAGES IN CAREGIVING: TURNING CHAOS INTO CONFIDENCE
By Gail Sheehy
Published by William Morrow, $27.95

Odds are you?re going to need this book someday.

It?s a grim topic: caring for a loved one until death. But Sheehy?s *Passages in Caregiving* is not a grim book. Instead, it is the kind of book that I want to press on friends and relatives, saying, ?You must read this!? But I don?t give it away, because it is a book I still need. There are resources I can make use of right now, like an elder exercise program I plan to do with my 90-year-old mother. And there are lists I will need someday, when someone I love enters the last phase of life.

Most of us will be called on to help someone live until they die. And it won?t be a small part of our lives. Sheehy says that five years is the average length of time that caregivers spend responsible for the care of an ill parent, spouse, sibling, child or friend.

Sheehy spent 17 years in this role, from her husband?s first bout with cancer to his death.

She has written a caregiver?s handbook for the long slog. It is directly addressed to the, by turns, frightened, determined, exasperated and exhausted. Subtitled ?Turning Chaos Into Confidence,? it is packed with practical advice and numerous helpful Web sites and checklists.

It is also a memoir of a loving marriage. Sheehy uses the story of the illness of her husband, editor and magazine creator Clay Felker, to show how two talented people kept on with productive lives for as long as possible, and planned for a productive life for Sheehy when she went on alone.

Sheehy?s great gift is to see societal patterns where individuals see only personal confusion, setbacks, rebirths or triumphs.

She names eight stages, or ?turnings? in the walk from diagnosis to death. She uses the metaphor of the labyrinth, and it is a good one. Walking a labyrinth requires reversing directions. The walker may feel lost, but following the path leads to the center and safely out again. Sheehy aims to show how the caregiver can walk through this experience and emerge whole.

She predicts ?Shock and Mobilization? at the first crisis, then settling in to the ?New Normal,? followed by ?Boomerang,? when families realize that the emergency measures need to be adjusted for the long haul. With long-term roles in place, main caregivers confront ?Playing God,? the tendency to believe they are wholly responsible for the patient?s health. Caregivers look for help when they realize ?I Can?t Do This Anymore.? The sixth turning is ?Coming Back,? when the caregiver begins to form a life beyond the sickroom. Seventh, ?The In-between Stage,? is when a patient is not sick enough to be hospitalized but not close enough to death

for hospice.

Finally there is ?The Long Good-bye.?

Twice before, Sheehy has charted life?s passages and influenced the national conversation. In 1974, she published *Passages: Predictable Crises of Adult Life*, giving names to new adult life phases of Americans up to age 50. Hugely popular, it was on *The New York Times* best-seller list for three years. In 1995, she published *New Passages*. She observed that many adults were making fresh starts at an age when people used to think they were old. The late 40s and early 50s she called the second adulthood. Again she hit the best-seller lists.

Public discourse was littered with stories of people in their fabulous 50s who, having made their millions, were at last opening their dream bed-and-breakfast in Costa Rica or Cape Cod. Younger boomers heard these stories with some envy and disdain. Most could not expect such affluence, but Sheehy was right to predict that late middle age would require most to retool and regroup.

Ignobly, I felt a bit of schadenfreude when I began *Passages in Caregiving*. Sheehy, the cheerleader for exhilarating second adulthood, had found, as so many others have, that caregiving stepped in to claim the time and energy planned for adventures in self-expression.

But Sheehy quickly put me to shame. Younger than the cohort of her first two books, I have at last aged into her target market. I need to know what she has to say. For example, her chapter on how and when to conduct a family meeting is worth 10 times the price of the book. She details what should be on the agenda: the patient?s prognosis, daily and weekly caregiving needs, financial concerns, family members? feelings and roles they might play, and then how they can arrive at problem-solving solutions. I recognized mistakes my family has made, places where we got it right, and ideas for how to do better next time.

And there will be a next time. Family caregiving is a predictable crisis of middle and later life. Sheehy quotes an AARP survey that indicated 65 million Americans are caring for someone with a long-term illness or disability. That is a lot of potential readers. Sheehy has helped shape the public conversation before. With *Passages in Caregiving*, she has done it again.

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