



Passages in Caregiving: Turning Chaos into Confidence

Gail Sheehy

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“One of those rare books that can drastically lighten even the heaviest of loads.”

—Rosalynn Carter

“Trust me: there is no better guide to caregiving.”

—Bill Moyers

Gail Sheehy, author of the groundbreaking *Passages*—which was a *New York Times* bestseller for more than three years—now brings us *Passages in Caregiving*. In this essential guide, the acclaimed expert on the now aging Baby Boomer generation outlines nine crucial steps for effective, successful family caregiving, turning chaos into confidence during this most crucial of life stages.

Passages in Caregiving: Turning Chaos into Confidence Details

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From Reader Review Passages in Caregiving: Turning Chaos into Confidence for online ebook

Jean says

A definite must read if you know of anyone who is currently a caretaker, will be yourself a possible caretaker for a family member in the future, and/or may have to provide services to someone who has or needs a caretaker. Gail goes through the caretaker stages when providing care for someone with a illness, dementia, or Alzheimer. Very informative with suggestions and resources.

Gloria says

I have not made my way completely through this book. That said, it is clear that this is one highly useful book in the world of caregiving and all that this entails. Chock full of pragmatic and specific advice for the act of caregiving, but also full of empathy about the changed lives of caregivers. This is one of those books people will consult when they find themselves in the middle of a crisis.

Julie says

I've read several of Gail Sheehy's books, and once again, she does not disappoint. I took copious notes because there was so much to learn and I'm sure I will need it for future reference. She covers it all, the medical, the personal struggle, the financial struggle, and facing the final outcome. This is such an important book to read while we debate what our health care system should look like, and how we, as a society, should set as our priorities. Her story gives a face to the statistics that get tossed about so easily.

Margery says

Sheehy kept journals during the 17 years her husband needed care. They were a busy couple, keeping residences in Berkeley (his job), N.Y.C. (her job), eastern Long Island (family get-away) and she commuted cross country as needed. She gives a straightforward account of emotions, solutions, searching for care, warning what insurance and Medicare will and will not pay for, palliative care when Hospice is not yet an option. I gave this four stars because I was a caregiver and needed her message "turning chaos into confidence."

Artemis Nitzband says

I prospered emotionally from reading this book. I am currently in the midst of caring for my mother and immersed in much of the same turmoil and chaos that Sheehy illustrates. By identifying these issues and finding that I am not alone in my conflicting feelings was extremely enlightening.

This book also was worth its weight in gold for the simple reason of passing on these 2 words...UNSAFE DISCHARGE. Sheehy exposes the issue of patients discharged from hospitals that ethically, legally and clinically should not be. It is a hidden factor in hospitals; many patients are discharged due to financial reasons. Doctors are forced and encouraged to do this. Nurses encounter moral and ethical dilemmas. Sheehy lets the cat out of the bag. These 2 words can force a doctor or hospital administration to back down and re-evaluate the situation.

This book can be frustrating in that Sheehy is quite wealthy and had means to care for her husband that most people don't. There is no way I can afford nursing care for my mother 24 hours a day. However, she does empathize and address that issue.

Definitely worth reading. Lots of insight and details on the issue of caregiving.

Sara says

This book should probably be called "Passages in caregiving for exceedingly well-connected and wealthy people, plus some advice on all the neat things you can buy to help you if you have money" It is chock-full of information on how to conduct a bi-coastal marriage when one of the partners is dying of cancer, how to deal with the heart-break of needing to sell your SECOND house when one of you needs around-the-clock care, how poignant it is when scores of grateful writers and students stream to visit with the sick spouse, the distress of figuring out how to take your partner to his favorite jazz club once he needs a wheelchair . . . in other words, situations most of Sheehy's readers would probably trade a kidney for.

As a narrative of her husband's decline and death, it is oddly static and uncompelling. Despite the theme of "passages," her treatment of her husband depends on pretty much the same repeated "but he had such a booming voice! Writers looked up to him!" chorus, regardless of what's going on.

As an advice book, the volume is much, much worse. Caregivers need to take care of themselves. Really? I bet no caregiver thought of THAT ever, without first ponying up \$14.95 for a book. The opening chapter advises the caregiver, "Breathe. Really. I know your mother always told you that, but she was right -- it really works."

And that is pretty much the caliber of this volume. Sheehy avails herself of every commonplace on longterm illness and dying floating around in the 21st century American ether, and then SELLS it to you because, folks, she lived through this while following Hilary Clinton around on the campaign trail, so she REALLY KNOWS. There are some pages where she rounds up possible services you could pay for, if you could afford them, and if you lived in a major metropolitan area where they are available. But if your problem happens to be that you can't afford to pay for an eldercare lawyer, or you don't live anywhere near one (or, if your problem doesn't actually involve the elderly, a scenario Sheehy claims to cover in her book but does not), then those lists probably are only going to make you feel more hopeless and frustrated.

But here's the deal: one of the Goodreads reviewers commenting on this book already pointed out, geez, if it's this hard for a wealthy woman with lots of connections and lots of family to deal with the longterm decline of her husband, what hope is there for the rest of us? That's the real truth of this book. Caregiving *isn't* manageable without longterm significant damage. Not for the wealthiest, and certainly not for the rest of us. As a writer with both cultural capital and access to influential politicians, Sheehy would have been doing a lot more good to lobby for widespread changes in employment policies and health care than she could ever do packaging up completely useless comments into a commodity for which other caregivers now

shell out their over-strapped cash.

Nancy Kennedy says

I truly think that you cannot grapple with the issues of caregiving until it becomes your role. I am not in that place, though I can see the day coming. I am sure that I will return to this book when I need the help and support -- and practical advice -- it offers.

Whatever book I read, I find that I take away at least one useful or memorable bit of information. In this Passages book, I was riveted by the chapter on the beneficial effect that creating art can have on dementia patients. I had never thought about that. There is so much a dementia patient cannot do that requires memory and complex step-taking -- like reading or crocheting or quilting -- and I've been casting around for meaningful activities to engage a person in. I am thinking about how to implement this in my family.

Then, of course, I was interested in Gail Sheehy's own story of her husband's illness and their life after his cancer diagnosis. It is always the personal story that draws me in, and from which I take the most lasting lessons. Hers is a journey many of us will travel, and she's a reassuring and practical tour guide.

Lisa says

This is about Gail Sheehy's life of being a caregiver for her husband and also stories from other caregivers. Great reference book, as she has given many agencies and their phone numbers for people that don't know where to begin.

Emil says

This wasn't that good, which I kind of knew from the start. There was some helpful stuff about coping with sudden changes in your life and the lives of the people you love, but it can from a very privileged space, with no voices of those being cared for. I felt like large parts of it were condoning, reinforced ableism, and assumed a lot of wealth and other privilege of those doing the caregiving.

But it was useful for me to read; to disagree with it, and to figure out what is important to me when it comes to the communities of care that we build for each other. Or really the first chapter or two and a couple paragraphs were useful. Now I just want to help write something way better.

Christy says

No one really expects it, but at some time or another, just about everyone has been—or will be—responsible for giving care, for a sustained period, to someone close to them. Gail Sheehy, who has chronicled every major turning point for twentieth-century Americans, as well as reported on everything from politics to

sexuality, knows firsthand the trials, fears, and rare joys of caregiving. In *Passages in Caregiving*, she takes you by the hand and shows you that you will get through this, and you will do the right things.

Sheehy identifies eight crucial stages of caregiving and offers insight for successfully navigating each one. With empathy and intelligence, backed by formidable research, and interspersed with poignant stories of her experience and that of other successful caregivers, *Passages in Caregiving* addresses the needs of this enormous and growing group. It is sure to become the touchstone for this challenging yet deeply rewarding period in your life journey.

Providing invaluable advice and guidance, this book examines the arc of caregiving from the first signs of trouble. Sheehy answers the most important questions to consider: How serious is it? What do I ask the doctor? How will this be paid for? What are our options? At the same time she offers new tips and strategies that you won't find anywhere else.

Most important, however, *Passages in Caregiving* points out that you don't have to be alone in this process. Included are countless resources and names of advocacy groups that are there to help even the most complicated of situations, many of which are woefully underutilized. With Gail Sheehy as your guide, *Passages in Caregiving* is sure to help turn a stressful, life-altering situation into a journey that can be safely navigated and from which everyone can benefit.

Judie says

HELP WANTED! Untrained family member or friend to act as advocate, researcher, care manager, and emotional support for a parent or spouse, sibling or friend, who has been diagnosed with a serious illness or chronic disability. Duties: Make medical decisions, negotiate with insurance companies or Medicare; pay bills; legal work; personal care and entertainment in hospital and rehab. Aftercare at home: Substitute for skilled nurse if injections, IV, oxygen, wound care or tube feedings are required. Long-term care: Medication management, showering, toileting, lifting, transporting, etc. Hours: On demand. Salary and benefits: 0. This appears on the second page of Chapter 1 of Gail Sheehy's *PASSAGES IN CAREGIVING*. She spends the remainder of the book into fulfilling the second part of the title: **TURNING CHAOS INTO CONFIDENCE**.

Based on her personal experiences while caring for her husband for seventeen years, she describes eight turnings that people in caregiving situations experience: Shock and Mobilization (Advocate with Authority); The New Normal (Turn Illness into Opportunity), Boomerang (Summon a Family Meeting), Playing God (Accept What You Cannot Change), "I Can't Do This Anymore!" (Create a Circle of Care), Coming Back (Replenish Your Lifelines), The In-Between Stage (Prepare Your Own Path to Comeback), and The Long Good-Bye (Love is Letting Go, Together). Each section provides not only a description of the stage and a diary of what she and her husband experienced, she talks about other people's experiences and provides very helpful strategies, including resources, for getting through them.

This book is written for the lay person who is trying to find their way through a difficult situation. It lets readers know they are not alone and gives them the tools the easy their burden. While not everyone will have all the experiences or go through all the stages, sometimes the end comes too quickly), there are suggestions that can help whatever stage you and the person for whom you are caring are currently dealing with.

My only suggestion would be to change the last part of the job description. There are immense benefits in being able to care for someone during the difficult periods of caring for them. This book makes the journey less difficult.

Starling says

The woman gets it. It isn't all that surprising since she lived the life of a long term caregiver with all of its ups and downs and with its isolation.

Yes, even a famous author can experience the isolation.

I had a very strange experience with this book since I was living the same conditions as I read the book. I got to the sections about the crisis when you realize there is no way to win, which Sheehy calls the center of the labyrinth just as I got to that center while sitting next to my husband in the hospital.

She explains what happens to long term caregivers very well and has good information and good advice. If there is something missing it is how one negotiates coming back out of the labyrinth probably because she is only just working her way out herself.

Caryl says

A must-read for anyone who is currently a caregiver or who can reasonably expect to become one in the future. It tells the story of Gail Sheehy's own caregiving for her husband for around 20 years, but it also tells many other stories of caregiving and of how individuals or families found ways to share the responsibilities. It describes resources that are available in many communities, as well as online. Most of all, it gives caregivers permission to take care of themselves as well as their cared-for one.

Lori says

Forget "It" and "Intensity" and "Rosemary's Baby" and every other horror story that has ever kept me awake at night. I am sure Gail Sheehy did not mean to do this -- but *Passages in Caregiving* disturbed me to my core. This is not the author's fault. She seems to be quite a compassionate, competent, strong and organized person. I know that she intended for the resources and information she provides in this book to be an aide and comfort to shell shocked family members who are wandering our Byzantine Health Care Maze in a stupor of grief and disbelief.

But I quailed in fear as I read how this successful writer, married to a well known Manhattan magazine editor, fell into such emotional, family, career and financial distress while caring for her spouse. If these well connected and well-to-do people experienced the disasters that they experienced...well...where exactly does that leave the rest of us?

Sheehy compares the experience of care giving to the winding corridors of a labyrinth...each layer turning in tighter circles until you enter that center of no return. I have been living in the outer rings of this labyrinth for the past couple of years as my parents age into cancer diagnoses. I recognize that I am heading deeper into this labyrinth and I dread what comes next. This book told it like it is. And that is admirable. You cannot sugar coat this stuff. But it also preyed upon my anxieties and even amplified them.

I did not actually finish this book...(more on this in a moment)

In order to illustrate each stage in the care giving cycle, Sheehy discusses what occurred in her own life with her husband, Clay Felker, (former editor of New Yorker Magazine) during that particular time. She balances her experience with some stories about other families coping with ageing parents or chronically/terminally ill partners.

Many of the people who offer their experiences in this book were either working high level jobs or else came from large families. As a person who has always earned a very modest income and who comes from a small family, I had trouble finding a situation I related to. What about care givers who are short on both cash and people to help?

I came to the dismal conclusion that the author may not have had much to say about people in that situation because there really is not much available to help them. In America, we love throwing people out there to fend for themselves and see how well they do. We act like we are still living in an agrarian society where everyone has 8 kids who can step in to run the family hospital. Never mind our long work weeks outside of the home that provide us with no extra income to handle the crushing costs of assistance. This is Catch-22 at its most bleak and draconian.

After reading (most of) this book the first time, I have arrived at my own personal rules about ageing:

1. I am not allowed to get sick before becoming eligible for Medicare
2. No heroics. I have only one child, myself, who came into my life in middle age. I cannot expect her to spend her 30s in hospitals with me going bankrupt.
3. I must keep eating kale and drinking green tea like my life depends on it...because it probably does.

In the case of caring for my parents, I have decided to check this book out of the library once again and skip the narrative. Instead, I will grab my pen and notebook and take down information for several extremely useful sounding web sites and resource titles that Sheehy provides at the end of several chapters and at the back of the book. This information should help me to organize and to make better decisions about helping them to find resources.

But hiring aides that cost \$800/day? Phoning a 'concierge' service? Bringing in a macrobiotic chef to cook for my mom and dad? This is the stuff of fantasy in my world. I'd do better to go out into my back yard tonight at midnight and wait for my fairy godmother to 'bippedy boppety boo' the whole nightmare away!

Maybe this is why the book scared me so badly. I realize that it is going to be mostly my sister and I stumbling through the maze in blind fear, providing the help my parents will definitely need while still juggling jobs and kids and everything else. I guess I already knew this. And I want to be there for them. But you are never fully prepared for this stage in life. And this book pretty much underscored the point that you never can be.

Julie says

This book is a MUST read for anyone who is the role of caregiver, whether it is taking care of an elderly parent, a child or a spouse. Sheehy offers concrete advice recommending coping strategies, agencies, and ways to get through some very difficult times. She is incredibly open about her own experience caring for her husband as he goes through 4 battles with cancer. I felt my roller coast emotions mirrored her experience as I go through a similar episode of life.
