



**C.A.R.E. PROGRAM**  
*Caregiver Assistance Resources and Education Program*

## **A Reading List for Caregivers**

### *Always on Call: When Illness Turns Families into Caregivers*

by Carol Levine, Editor

This book is less a how-to and more a how-come. It uses real-life stories to discuss the issue of caregiving in the context of major changes – both policy and practice – to our health care system. Its essays cover the financial impact of caregiving, resolving conflicts with the health care team, models of innovative caregiving, and a review of government policies that affect family caregivers.

### *Chicken Soup for the Soul: Family Caregivers: 101 Stories of Love, Sacrifice, and Bonding*

by Joan Lunden and Amy Newmark

Reading about the compassion, sacrifice, and perseverance of other caregivers reminds us that we aren't alone. This inspirational collection co-written by A Place for Mom spokesperson Joan Lunden offers 101 stories of support, love and encouragement for family caregivers of all stripes, including spousal caregivers and sandwich generation caregivers.

### *Helping Yourself Help Others: A Book for Caregivers*

by Rosalynn Carter and Susan Golant

Look for empathy in this book, written by the former first lady. Rosalynn Carter thinks caregiving is such a critical issue that she has established an institute to research policies and practices. Using real-life caregiver stories, the authors demonstrate that caregiving has meaning and purpose, especially when caregivers get the support they need.

### *Things I Wish I'd Known*

by Deborah J. Cornwall

Practical lessons drawn from caregivers' experiences are woven with their own words and most intimate feelings to forge a compelling narrative about the full range of issues you'll face as a caregiver or patient.

### *Caregiving: The Spiritual Journey of Love, Loss, and Renewal*

by Beth Witrogen McLeod

As a former caregiver herself, Beth Witrogen McLeod can empathize with the rollercoaster of emotions that many caregivers face daily. She's shared the ride and offers tips on ways to hold on through the ups and downs.

### *When Life Becomes Precious: The Essential Guide for Patients, Loved Ones, and Friends of Those Facing Serious Illness*

by Elise Babcock

Dealing with difficult conversations is the substance of this book, from times caregivers may not know what to say to times that call for tough conversations. Babcock's suggestions, along with practical resources, support clear communication between patients and the people who love them.



**C.A.R.E. PROGRAM**  
*Caregiver Assistance Resources and Education Program*

*An Uncertain Inheritance: Writers on Caring for the Family*

by Neil Casey

Authors such as Jerome Groopman, M.D., Julia Alvarez, and 16 others, all of whom have cared for their own family members or been the object of care, give an honest and sometimes funny view of their experiences in this book of essays.

*You'd Better Not Die or I'll Kill You: A Caregiver's Survival Guide to Keeping You in Good Health and Good Spirits*

by Jane Heller

Caring for an ill spouse is never easy, but with help from some celebrity friends and caregiving experts, Heller successfully chronicles the lighter side of the 20 years she has spent caring for her husband, who has severe Crohn's disease.

*The Caregiving Wife's Handbook*

by Diana Denholm

As a psychotherapist and a wife who spent most of her marriage caring for a husband with cancer and congestive heart failure, Denholm offers practical advice for dealing with the range of emotions that face spousal caregivers.

*No Saints Around Here: A Caregiver's Days*

by Susan Allen Toth

A memoir chronicling travel writer Toth's journey as a caregiver for her spouse. Her husband's Parkinson's disease and, over time, his dementia, poses wrenching challenges ranging from loneliness and despair to the inevitable disappearing of the time left with one's loved one. Practical questions, too, are a part of this story: ensuring nutrition and physical comfort for someone who may resist care.

*The Caregiving Wife's Handbook*

by Diana Denholm

Denholm, a psychotherapist who cared for her husband during his battle with cancer and heart disease, profiles the stories of six women in similar situations. Being a spousal caregiver poses a unique set of challenges, from emotional upsets to questions about intimacy. The survival tips and personal anecdotes in this book will help remind spouses that they are not alone, and they can make it through the difficulties of caregiving.

*A Bittersweet Season: Caring for Our Aging Parents – and Ourselves*

by Jane Gross

This book by former *New York Times* reporter Jane Gross is a personal memoir of caring for aging parents and a how-to primer for navigating elder care. The author describes admitting to wishful thinking that her mother just hurry up and die, her loneliness and emotional pain, and sibling relationship challenges.

*Can't We Talk About Something More Pleasant?*

by Roz Chast

Laughter is a major stress reliever, and in her book, a memoir in cartoons, Chast uses humor and honesty to tackle the day-to-day issues experienced by a caregiver of aging parents, such as dealing with assisted living, dementia symptoms and other caregiver challenges.



**C.A.R.E. PROGRAM**  
*Caregiver Assistance Resources and Education Program*

*Caring for Your Parents: The Complete AARP Guide*

by Hugh Delehanty and Elinor Ginzler

This guide explores the practicalities of health care, estate planning, assisted living and home safety, and combines expert advice with first-hand stories from caregivers of elderly parents. It also contains helpful checklists and lists of resources.

*The Caregiver's Survival Handbook: How to Care for Your Aging Parent Without Losing Yourself*

by Alexis Abramson

One of the frustrating aspects of being a woman in the “sandwich generation” is feeling underappreciated – feeling like your own needs are not being met while you’re caught in between meeting the needs of both children and aging parents. This book offers practical caregiving information for sandwich-generation women, along with advice on dealing with the emotional challenges of caregiving, like work-life balance and getting help when you need it.

*When the Time Comes: Families with Aging Parents Share Their Struggles and Solutions*

by Paula Span

Span is a journalist, and she interviews a range of families as they struggle through the transitions of caring for aging parents. Many face the difficult decision of whether to care for their parents at home or through assisted living, and all of them are searching for answers to common questions about elder care.

*The Madwoman in the Volvo: My Year of Raging Hormones*

by Sandra Tsing Loh

A memoir about being what Loh calls a “triple-M” — middle-aged mother in menopause — this book also talks about her experiences as a Sandwich Generation caregiver trying to balance her own well-being with the complications of raising kids at the same time she’s taking care of an elderly father with dementia.

*They're Your Parents, Too! How Siblings Can Survive Their Parents' Aging Without Driving Each Other Crazy*

by Francine Russo

Dealing with siblings and other family members can be complicated, and Russo’s book offers advice for dealing with the transitions of aging as a family. Sibling rivalries can add an entirely new dimension to the already-existing problems of caregiving: Who’s going to take charge? What about long-distance caregiving issues? What if one sibling doesn’t want to face end-of-life discussions?

*Navigating Life with a Brain Tumor*

by Lynne P. Taylor and Alyx Porter Umphrey

Providing readily accessible information and real-world encouragement to people living with primary and metastatic brain tumors, this book discusses the basics of brain tumors, types of tumors, management of different tumors, related symptoms, treatments and side effects, the role of medical team members, and coping strategies from initial diagnosis throughout the course of the illness.



**C.A.R.E. PROGRAM**  
*Caregiver Assistance Resources and Education Program*

## **Caring for a Loved One with Alzheimer's Disease or Dementia**

*The 36-Hour Day: A Family Guide to Caring for People Who Have Alzheimer's Disease, Other Dementias, and Memory Loss*

by Nancy L. Mace and Peter V. Rabins

The 36-Hour Day is often referred to as the "gold standard" book for families who are caring for someone with Alzheimer's or dementia. It's a care guide that has practical tips and information to improve the lives of people with dementia and also to help caregivers cope with their own emotions and needs.

*Learning to Speak Alzheimer's: A Groundbreaking Approach for Everyone Dealing with the Disease*

by Joanne Koenig Coste

A practical approach to the emotional well-being of both the person with dementia and their caregiver. The author emphasizes relating to people with dementia in their own reality and focuses on improving communication – proven successful with thousands of people living with dementia.

*Creating Moments of Joy Along the Alzheimer's Journey: A Guide for Families and Caregivers*

by Jolene Brackey

The author's vision is that we'll focus on creating moments of joy that put a smile on their face or a twinkle in their eyes. Even if they won't remember what we said or did, the positive feelings will stay with them.

*Surviving Alzheimer's: Practical tips and soul-saving wisdom for caregivers*

by Paula Spencer Scott

In her book, Paula Spencer Scott talks about what every family caregiver needs to know – how to help someone with dementia without sacrificing yourself.

*Activities to do with Your Parent who has Alzheimer's Dementia*

by Judith A. Levy, EdM, OTR

Everyone needs to feel engaged and entertained, but finding activities that someone with dementia can enjoy is a constant challenge. The activities in this book help maintain your parent's self-care skills, mobility, and socialization. The tasks encourage success, boost self-esteem, and give you different opportunities to interact with your older adult.

*Chicken Soup for the Soul: Living with Alzheimer's & Other Dementias: 101 Stories of Caregiving, Coping, and Compassion*

by Amy Newmark

Caring for someone with Alzheimer's or dementia can make you feel lonely and isolated but you're definitely not alone in this. This book has 101 encouraging and inspiring stories by caregivers. It's a source of support and encouragement throughout the caregiving journey.



**C.A.R.E. PROGRAM**  
*Caregiver Assistance Resources and Education Program*

*Still Alice*

by Lisa Genova.

After reading this heartbreaking novel about a 50-year-old wife, mother and Harvard professor facing the diagnosis of early onset Alzheimer's, you'll never look at the disease the same way again.

*Beyond Forgetting: Poetry and Prose about Alzheimer's Disease*

by Holly J. Hughes

This collection brings together the work of 100 contributors – doctors, nurses, social workers, hospice workers, daughters, sons, wives and husbands – who have chosen to confront the topic of Alzheimer's through personal stories, poems and short prose pieces. Each writer has been touched in some way by the disease, and the range of literary contributions by both formal and informal caregivers is touching and deeply moving.

*A Gradual Disappearance*

by Elizabeth Lonseth

Both guide and memoir, this book is equal parts personal stories and practical advice for family caregivers by an experienced family caregiver. The author's parents and parents-in-law were struck with dementia. The book is specifically tailored to caregivers of those with Alzheimer's, with chapters on topics such as dealing with the initial diagnosis and coping with difficult behaviors.

*Inside the Dementia Epidemic: A Daughter's Memoir*

by Martha Stettinius

More than simply a memoir of one woman's experiences as a sandwich-generation caregiver, this book also lays out the stages of caring for a parent with dementia as her mother progressed from needing home care to requiring more advanced memory care and nursing.

*The Seasons of My Mother: Memoir of Love, Family, and Flowers*

by Marcia Gay Harden

In this lyrical and deeply moving memoir, one of America's most revered actresses weaves stories of her adventures and travels with her mother, while reflecting on the beautiful spirit that persists even in the face of her mother's struggle with Alzheimer's disease.

## **Caring for a Loved One with Cancer**

*Couples Confronting Cancer*

by Joy L. Fincannon, R.N., M.S., and Katherine V. Bruss, Psy.D.

This book, published by the American Cancer Society, addresses the changes couples may experience when cancer enters their lives. It suggests pathways through conflicts and includes exercises that can help couples cope with special problems. The authors aim to help partners deepen their connection with each other so that they face the challenge of cancer as a team.



**C.A.R.E. PROGRAM**  
*Caregiver Assistance Resources and Education Program*

*Caregiving: A Shared Journey*

by Dianne Thompson

A personal memoir of a caregiver's view of life when her husband was diagnosed with an aggressive and ultimately fatal cancer. The diagnosis and treatment brought challenges to this couple as they adapted to the many changes illness brings into a marital relationship. Their story is told with honesty, wit, and wisdom.

*Cancer Caregiving A to Z: An At-Home Guide for Patients & Families*

American Cancer Society

Accessing information is easy in this book, organized in an A-to-Z format for quick referencing. The listings cover a broad range of critical topics and the book includes both checklists and "what-to-do-if" guides.

*Passages in Caregiving: Turning Chaos Into Confidence*

by Gail Sheehy

Writing of her journey caring for her husband, who died of cancer, the social anthropologist and best-selling author leads readers through the emotional caregiving passages of a fragmented health care system.

*Caregiving: A Step-by-Step Resource for Caring for People with Cancer at Home\**

by Peter S. Houts and Julia A. Bucher

Turn to this book when you're at a loss as to how to solve a problem, be it managing a side effect of chemotherapy, wrangling with insurance, or trying to shore up a gloomy patient (or yourself). The book includes a six-step plan of action for typical problems caregivers might encounter, as well as a rich list of resources.

*Breast Cancer Husband: How to Help Your Wife (and Yourself) during Diagnosis, Treatment, and Beyond*

by Marc Silver

When Silver's wife was diagnosed with breast cancer, he searched for information that could help him help her. When he didn't find it, he created his own road map for men looking for direction. Using humor, expert interviews, his own story, and the stories of other couples, Silver tackles such issues as talking to young children, the male "fix-it" mentality, and an honest discussion of sex following breast cancer surgery.

*The Power of Two: Surviving Serious Illness with an Attitude and an Advocate*

by Gerri and Brian Monaghan

This book couples inspiration with practical advice. It's both the story of what it meant to be a couple fighting cancer together and the story of how they fought.



**C.A.R.E. PROGRAM**  
*Caregiver Assistance Resources and Education Program*

## **Caring for a Loved One at the End of Life**

*Final Journeys: A Practical Guide for Bringing Care and Comfort at the End of Life*

by Maggie Callanan

Detailed information about difficult decisions facing caregivers and patients at the end of life are only part of this important book. Callanan also discusses caregiving in a "wounded relationship," the role of hope, and the impact of culture on families caring for a loved one at the end of life.

*The End-of-Life Handbook*

by David Feldman and Stephen Andrew Lasher, Jr.

Caregivers will find answers that might help them feel a modicum of control in a situation with none. Making sense of bad news, how to advocate for pain and symptom relief, and who on the medical team does what, are some of the topics covered.

*Tuesdays with Morrie*

by Mitch Albom

Newspaper sports columnist Mitch Albom recounts the time spent with his 78-year-old sociology professor, Morrie Schwartz, at Brandeis University, who was dying from amyotrophic lateral sclerosis (ALS).

*The Five People You Meet in Heaven*

by Mitch Albom

This book follows the life and death of a maintenance man named Eddie, who was killed and sent to heaven. He encounters five people who had a significant impact upon him while he was alive.