

Most of us are not prepared to be caregivers. We take on the role with love and good intentions, but we may experience feelings we never expected. Caregivers may encounter a range of feelings and concerns as they move along the path of caregiving.

There can be some surprisingly good feelings:

- **Feeling closer and connected** to your loved one
- **Feeling good** about what you are doing
- **Feeling satisfied** that you can help
- **Confidence and feeling more competent** than you thought you were
- **Feeling some inspiration** from the strength of your loved one

Some feelings are intense. Caregivers may be surprised that they feel overwhelmed, guilty, sad, tearful, or even perplexed. **But these feelings are normal.**

- **Stress.** Stress can build up without our realizing it, when we worry a lot, become fatigued, or feel overwhelmed by responsibilities.
- **Worry.** It's common to worry about a diagnosis, weigh treatment decisions, or even wonder if treatment is working.
- **Frustration.** You may have too much to do and no downtime, be unsure about what you're doing, or feel unappreciated. It helps to talk about these situations – even if talking about personal experience isn't your style.
- **Feeling overwhelmed.** You may wonder if you're living up to your own expectations of doing a good job.
- **Feeling alone.** Sometimes, the special connection you had with your loved one may seem lost.
- **Sadness.** Taking care of someone you love can cause deep sadness: for what is happening to your loved one and yourself, and for the changes in both of your lives.
- **Grief.** Grief happens whenever there is loss, including seemingly small losses, such as the loss of your normal routine. We also grieve when a loved one has changes that affect his or her functioning.
- **Anger.** You may feel anger about the unfairness of the cancer diagnosis, difficulties caused by treatment, or isolation you may feel as a caregiver
- **Guilt.** Guilt may come from feelings you didn't anticipate, such as wanting this stressful experience to end or being the one who is not ill.

It's important to remember that most caregivers feel some or all of these feelings at times when caring for a loved one with cancer. While caregiving can be difficult, it can also be one of the most meaningful and rewarding things you'll ever do.

Take Care of Yourself

If you're like most caregivers, you'll stop reading this right about the time you figure out that this section is just for you.

Yes, you!

As caregivers, we tend to put ourselves at the bottom of our "to-do" list. What are some possible reasons that we put the needs of others ahead of our own?

- We're capable and competent and don't like to ask for help.
- We don't want to disappoint the people we love.
- We refuse to let cancer define our life.
- We may worry that if we ever stopped long enough to consider what lies ahead, we might fall apart.

Here's why taking care of *yourself* is important.

- You'll take better care of the people you love when your own needs are met.
- You'll be in a better position to make difficult decisions or have complicated conversations.
- You'll have the mental energy to shift gears when you encounter something unexpected.

Finding the physical and mental energy to take care of yourself isn't easy, but it needn't be time-consuming. Sometimes, simple things can keep you grounded (such as giving or getting a big hug.). Putting your life into balance is what gives you the energy to get your loved one to the next appointment, share a concern, or cook a favorite dish. Consider cancer as a marathon; train for the long haul. In the following sections, we'll look at how to get started.

Take Care of Your Mind

You may find yourself:

- Living with anxiety
- Easily irritated at small things
- With so little ability to concentrate that you can't finish a bestseller
- Being impatient with people you love
- Feeling two very different ways about the same thing
- Feeling "down"

Banishing these feelings may not be realistic. Keeping them in perspective might. Caregivers say the following steps have helped them balance out mental stresses:

Write it out: Keeping a log or written journal can be a safe place to struggle with feelings and frustrations. Simply getting something on paper can help provide perspective.

Use your ears: Try tapes or CDs that can help you breathe, relax, or visualize your way through stress. Your local library should have tapes or CDs that you can borrow. Patients at Dana-Farber can check out tapes and CDs at the Eleanor and Maxwell Blum Patient and Family Resource Center, located on the first floor of the Dana building.

Let others help: There are people in your life who want to help. Make a list of tasks you need help with. For example, people can shop, walk the dog, or keep your loved one company while you have time to yourself. (For more on this topic, visit www.dana-farber.org/caregivers and read “How to Create a Caregiving Plan.”)

Educate yourself: Use reputable Web sites and nonprofit cancer advocacy organizations to learn more about cancer, treatment options, and managing side effects. You can also learn more at Dana-Farber’s Blum Patient and Family Resource Center.

Consider joining a support group: Caring for someone can be a lonely experience, and one that non-caregivers may not fully appreciate. Talking with others who are sharing your experience can help reduce a sense of isolation.

Seek counseling: If support groups aren’t your thing or are unavailable, consider individual counseling. Start by checking resources available to you at your own oncology center. Or contact your insurer to find a therapist covered by your policy.

To find a therapist familiar with issues facing people who are dealing with cancer, contact the American Psychosocial Oncology Society’s toll-free helpline at **866-276-7443** or e-mail info@apos-society.org. Additional counseling resources for caregivers are listed on the Dana-Farber Web site at www.dana-farber.org/caregivers.

Talk with your doctor: If you find yourself easily irritated, having trouble making decisions, or unable to account for your day, you may be feeling depressed or anxious. If these feelings are interfering with your daily activities, consider talking with your doctor about medication that may help.

Take Care of Your Body

Caregiving can take a toll. Our bodies pay a price for providing physical assistance to frail patients, not getting enough sleep, or substituting snacking for a meal.

Caregivers say these ideas have been helpful:

- **Exercise:** Anything from a yoga class to a short stroll can discharge the physical tension that accumulates from sitting in waiting rooms or perching by a hospital bed. Borrow a yoga video or audiotape, or drop in on an exercise class to help your body unwind.

“I found attending a support group very beneficial. It makes you feel less alone. I learned from members how important it is to take care of yourself, to do outside activities, to not be a caregiver one hundred percent of the time.”

— Gail, caregiver of a patient with myeloma

- **Stretch:** No time to exercise? Rolling your neck, stretching your legs, or touching your toes to stretch your back doesn't require much time or space. Give it a try. Caregivers whose loved ones are being treated at Dana-Farber can even participate in free movement and exercise classes offered through the Leonard P. Zakim Center for Integrative Therapies, located in the Shields Warren Building.
- **Maintain your own health:** Take your own medications, maintain your checkups, and see your doctor regularly. You'll be better able to care for your loved one if you feel well.
- **Listen to your body:** If you don't feel well, check things out. Don't be too quick to assume fatigue or pain are related to stress. Call your doctor if symptoms persist.
- **Eat well:** You might feel better when you maintain your own level of healthy eating. Caregivers whose loved ones are being treated at Dana-Farber are welcome to participate in nutrition seminars. Learn more at www.dana-farber.org/nutrition.
- **Sleep:** If the patient isn't sleeping well, it's likely that you're not either. Ask doctors to address sleep problems, and consider consulting a sleep specialist if problems persist.
- **Treat your body right:** Whether it's a hot bath or massage, do something special for your body from time to time. Even scented lotion or a spicy aftershave can be a nice change.

"I followed some practices that I found in The Artist's Way, by Julia Cameron, and wrote morning pages, almost like writing in a journal every morning. But I didn't use these pages to vent. I tried to turn negative things into positive things. I also wrote down affirmations."
 — Kate, wife of a patient with bone cancer

Take Care of Your Spirit

Maintaining hope, finding meaning, and feeling purposeful in the face of cancer can be among caregivers' most challenging tasks. Some people find solace through prayer, at religious services, or by talking with a member of the clergy. Others find sustenance by meditating, contemplating nature, volunteering, or exploring a creative pursuit.

Caregivers say these activities have helped them maintain spiritual balance:

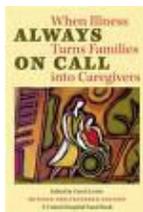
- **Connect with your spiritual community.** Try something that may help you feel calm: talk to a clergyperson or hospital chaplain, attend a religious service, or find a healing ceremony.
- **Cultivate gratitude.** There may be days when the only thing that you can find to be grateful for is that the day is over. Whether you're grateful for something as small as scoring a good spot in the hospital parking lot, or something as large as the effectiveness of a new medication, a sense of gratitude can help you maintain hope.

- **Share that gratitude with others.** A simple thank-you to your nurse, to the parking attendant, or anyone who has shown you or your loved one a kindness can make someone's day and often boosts you, too.
- **Read uplifting materials or religious texts.** Stories of hope, daily affirmations, or holy writings may all help strengthen your spirit. The Blum Patient and Family Resource Center's collection includes books on spirituality as well as inspiring personal stories.
- **Listen to music.** Whether it's a snappy show tune to lift your spirits, gospel to stir your soul, or classical music to soothe you, music is good company.
- **Get in touch with nature.** Contemplating natural beauty can be calming and remind you of your connection to the larger world.
- **Forgive yourself.** Over the course of an illness, it is likely that you'll spend some time looking backwards, questioning yourself, or second-guessing your actions. When we seek order and control in an experience where there is none, we may create our own cause and effect. Blaming yourself or fretting over a shortcoming makes caregiving harder. Ask for forgiveness, or forgive yourself.

"On my walks, I took photographs of beaches, both as a distraction and because they were beautiful. Some of them have since won prizes."
— Kate, wife of patient with bone cancer

Books about Caregiving

Books marked with an asterisk [] by their title are available for lending from the Eleanor and Maxwell Blum Patient and Family Resource Center at Dana-Farber.*

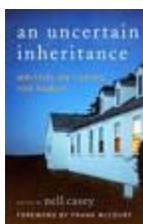


Always on Call: When Illness Turns Families into Caregivers*

Edited by Carol Levine

Less a “how-to” and more a “how-come?” this book uses

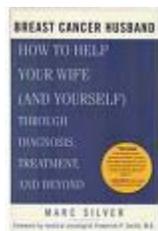
real-life stories to discuss caregiving in the context of major changes to our health care system. Its essays cover the financial impact of caregiving, resolving conflicts with the health care team, and models of innovative caregiving.



An Uncertain Inheritance: Writers on Caring for the Family

Edited by Neil Casey

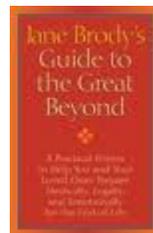
In this book of essays, authors who have cared for their own family members (or been the object of care) give an honest, sometimes funny view of their experiences.



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

Marc Silver

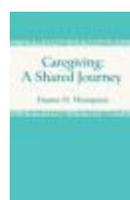
When Silver’s wife was diagnosed with breast cancer, he searched for information that could help *him* help her. When he didn’t find it, he created his own road map for men looking for direction. Using humor, expert interviews, his own story, and the stories of other couples, Silver tackles such issues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



Jane Brody’s Guide to the Great Beyond

Jane Brody

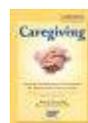
Though the subject is sobering, this practical book’s tone is compassionate and upbeat. With information on everything from advanced directives to organ donation, the book also tackles more complex subjects: living with a bad prognosis, caregiving at end of life, communication, and when doctors disappear.



Cancer Caregiving: A Shared Journey

Dianne Thompson

This personal memoir is 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.



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

Peter S. Houts and Julia A. Bucher

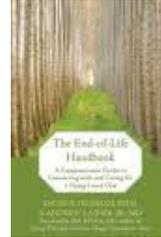
Turn to this book when you’re at a loss as to how to solve a problem, be it managing a side effect of chemotherapy, wrangling with insurance, or trying to shore up a gloomy patient (or yourself). The book includes a six-step plan of action for typical problems caregivers might encounter, as well as a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



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

American Cancer Society

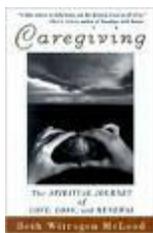
Accessing information is easy in this book, organized in an A to Z format for quick referencing. The listings cover a broad range of critical topics, and the book includes both checklists and “What-To-Do-If” guides.



The End of Life Handbook

David Feldman and
Stephen Andrew Lasher Jr.

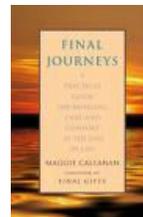
Caregivers will find answers that might help them feel a modicum of control in a situation without any. Making sense of bad news, how to advocate for pain and symptom relief, and who on the medical team does what are just some of the tips caregivers will find in these pages.



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

Beth Witrogen McLeod

As a former caregiver herself, the author can empathize with the rollercoaster of emotions that many caregivers face daily. She offers tips on ways to hold on through the ups and downs.



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

Maggie Callanan

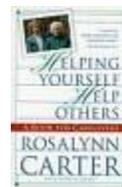
Detailed information about difficult decisions facing caregivers and patients at the end of life is only part of this important book. Callanan also discusses caregiving in a “wounded relationship,” the role of hope, and the impact of culture on families caring for a loved one.



Couples Confronting Cancer

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

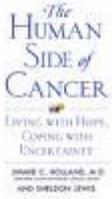
Published by the American Cancer Society, this book addresses the changes couples may experience when cancer enters their lives. It suggests pathways through conflicts, and includes exercises that can help couples cope with special problems. The authors aim to help partners deepen their connection with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



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

Rosalynn Carter and Susan Golant
Look for empathy in this book written in part by former first lady Rosalynn Carter. She

believes that caregiving is such a critical issue, she has established an institute to research its 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. Carter includes resources to help them do just that.

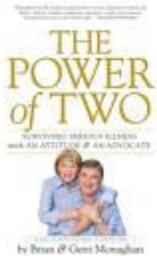


**The Human Side of Cancer:
Living with Hope, Coping with
Uncertainty**

Jimmie C. Holland, MD, and
Sheldon Lewis

Psycho-oncology pioneer

Jimmie C. Holland, MD, guides people with cancer and their caregivers through all aspects of the experience, including strategies for coping with anxiety, communicating with the health care team, and living with uncertainty. The author also includes discussions of the psychological effects of radiation, surgery, transplants, and other treatment modalities. Although caregivers are not the book's main audience, they will likely find its insights and information useful in understanding the experience of their loved one.

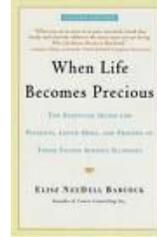


**The Power of Two:
Surviving Serious Illness
with an Attitude and an
Advocate**

Gerri and Brian Monaghan

This book couples
inspiration with practical

advice. It's both the story of what it means to be a couple fighting cancer together, and the story of how they fought. Gerri's top tip: "Trust your instincts."



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

Elise Babcock

Dealing with difficult

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