

# Your Ultimate Caregiving Guide: Essential Tools and Insights for Every Experience



## Table of Contents

Pg 1	Introduction
Pg 2	Starting Out
Pg 3	Practical Advice for Tough Conversations
Pg 5	Taking Action
Pg 6	Care Circle Coordination
Pg 8	Activity: Define Strengths Within the Care Circle
Pg 9	Never Enough Time
Pg 11	Activity: What Do You Need?
Pg 12	Resilience
Pg 13	How to Cope with the Toll of Caregiving
Pg 15	Getting Professional Help
Pg 16	Settling In
Pg 17	5 Critical Legal Documents for Caregivers
Pg 19	Pivoting
Pg 20	Is Home Care the Right Choice?
Pg 22	Resolution and Meaning
Pg 23	Preparing Yourself
Pg 24	Moving Forward
Pg 25	Other Caregiver Support Resources We Love
Pg 26	In Closing

## Introduction

Whether you've been a caregiver for many years or are starting your experience *today*, you've undoubtedly realized that **caregiving is complicated**. It's a demanding experience – physically and mentally — and can bring with it a host of emotions for everyone involved. That's why at Caregiver, it's our mission to provide you with the support and guidance you need to harness your inner resilience and strength. That includes reminding you:

- **You are not alone.** There are over 50 million informal caregivers in the US. And, as caregiving becomes more valued, more resources are becoming available.
- **You can define your own path.** In reality, roles and responsibilities look considerably different across the caregiving experience. *Every situation is unique, and therefore everyone's journey is their own.*
- **Joy can ultimately exceed hardship.** Studies have found that caregivers experience joy when they spend quality time with those requiring care. Knowing a care recipient is safe, providing support, and witnessing improvement in another's quality of life benefit the caregiver and the person they are caring for.

As part of our mission to support caregivers where they are, we created this **Ultimate Caregiving Guide** filled with resources for every stage of the caregiving experience: Starting Out, Taking Action, Resilience, Settling In, Pivoting, and Resolution and Meaning. These resources will help you address the practical and emotional challenges you may face throughout every stage of caregiving.

Download it, print it out, mark it up — this Guide is yours to use in any way that helps you and meets you **where you are right now as a caregiver**. We hope it enables you to feel practically equipped, emotionally supported, and empowered in your role.

## Starting Out

An introduction to your journey as a caregiver.



### Practical Advice for Tough Conversations

If you're having trouble finding a place to begin, you're not alone. But, you will be better positioned to help your care recipient if you know what's important to them as they require more care. Here's what we suggest:

**Look for opportunities.** *Meet your care recipient where they are. Listen to the cues when you're offered a moment to gently ask questions.* If they mention discomfort or the need for assistance, you can say, "I don't want you to lose your dignity when you need help. I want to respect your independence and not step on your toes. I want to collaborate with you during this time."

**Find conversation starters.** You can use an article you read or a conversation with someone else as an introduction. For example: "I read an article online the other day about gathering important documents in one place. Just in case, can you show me where yours are?" Or, "I've been considering all the stairs in this house. What are your thoughts about that challenge?"

**Listen.** You don't have to provide solutions. You don't have to make things better. It can be quite a gift for your care recipient to express their worries and fears. Consider that, perhaps, acknowledging death can be a comfort. It shows your strength in helping them face a difficult path. Listening will build trust and connection. Follow their lead. Summarize what they said so they feel heard and use similar language. "Let me make sure I'm getting this right. You said..."

**Be patient.** Sometimes, if you can wait and stay silent longer than what's comfortable, your care recipient will break the silence. We tend to want to reassure people immediately. It's not easy to sit in silence. When they say something that's hard for you to hear, sometimes, if you just stay in the silence long enough, they'll keep going.

**Be a partner.** To every extent possible, the person you're caring for should be centered in the conversation. They should fully participate in the discussion about their needs and desires. A big fear of care recipients is losing their autonomy. Many older people who were once known for their strength and competence feel like their family and friends are now treating them like children, and they are losing agency over their own lives.

**Find support.** Now is an excellent time to bring friends and family together to create a circle of care (what we call your "Care Circle") around the person cared for, so you don't have to do it alone. Keep in mind other sources of help, including doctors, nurses, and social workers.

**Keep trying, keep talking.** We can't underscore how difficult this can be for everyone involved. If you feel you missed an opportunity or handled a conversation poorly, there's room to circle back. You can say, "You brought this up, and I'm sorry I didn't address it. Tell me more about how you're feeling. I want to know." No one is going to be perfect on this journey. There will be a lot of trial and error. Apologies can go a long way.

There can be an expectation or need to feel we have it all under control. Sometimes, the best way to engage in a challenging conversation is to simply admit how hard it is, and you're not sure how to do it, but you want to.

**Look ahead.** Know the kinds of conversations you'll need to have over time. You will have to talk to your care recipient about many logistical issues, some of which will be harder than others. Money is one of the most important — yet hardest — conversational hurdles to scale. You'll need to learn where essential documents are stored and have access to passwords, bill payment portals, and bank accounts. Other challenging topics include care facilities, living wills and life support, funeral arrangements, legacy items, and your need — as a caregiver — to take time for yourself.

**Take note.** *Acknowledge that much of the difficulty in discussing these topics is about something other than your inability or fear. Instead, it arises out of love, concern, and a desire to protect someone who needs care.*

## Taking Action

Create a foundation for caregiving.



## Care Circle Coordination

*Coordinating a team to assist with caregiving will be easier once you identify the skills and experiences needed to help you allow the way.*

**Track roles and responsibilities.** There will be people with different abilities and levels of commitment within your Care Circle. It can become confusing to keep track of everyone's involvement. Consider mapping out care relationships and noting who said they could address what and when.

**Communication is an important element to tackle early on.** It can be tiring and time-consuming to care for another person. Communicating with others in the Care Circle about how you're caring for someone can also be exhausting. Make sure everyone knows how to stay in touch via text, email, video conferencing, etc. Decide who should be updated regularly.

**Delegation can save the day.** Caregiver burnout is real. People who experience it most often don't (or can't) delegate. Being direct about your needs is the best alternative to burnout.

- [How to Delegate Tasks Effectively \(and Why It's Important\)](https://www.meistertask.com/blog/delegate-tasks-effectively) (<https://www.meistertask.com/blog/delegate-tasks-effectively>) by MeisterTask

**Consider regular meetings.** Perhaps all members of the Care Circle meet every other week, and some members communicate once a week. A regular pattern of group communication can help you delegate and avoid burnout or resentment.

**Have a plan.** Propose a standard meeting agenda to include discussion of general feelings and concerns, prioritizing care recipient needs, organizing planned assistance, and addressing new or unanswered questions, etc.

**Include fun, community-building activities.** Planned activities can lighten the mood, help establish consensus, and build feelings of unity.

**Take notes, especially for agreements.** Documentation can be critical to fostering accountability and minimizing confusion. Arrangements determined during meetings should be followed by digital or hard copy distribution of simply formatted written agreements. Remember to save notes in a central, secure location.



**Ensure responsibilities are fair.** Providing care might be the most critical “group project” you’ve ever participated in. Like all group projects, some people do more work than others. A natural but unequal balance may result. Still, there are ways to acknowledge, recognize, accommodate, and compensate for an uneven balance of work. As you contemplate transparency and equity regarding roles and responsibilities at the beginning of a caregiving journey, consider asking your core team to record their time spent caregiving over a few weeks. Plan to discuss results at an upcoming meeting and consider suggesting everyone revisit the same activity over time to ensure the delegation of tasks remains fair.

## Activity: Define Strengths Within the Care Circle

To support care coordination efforts, list Care Circle member names alongside the skills and resources they bring to the team. Use this table as a guide:

Resource	Skills & Experiences	Restrictions
<i>Example: Mya</i>	<i>Grocery shopping, gardening</i>	<i>Only available on the weekends</i>

### Never Enough Time

For some, going to work provides a needed break from talking about things like medication, catheters, or a care recipient's declining mental health. Caregivers can, to some degree, experience "normal" life. Work can be where they regain a sense of expertise and control — confident in their abilities and making decisions with clear outcomes.

In reality, however, there are many tasks that caregivers need to perform during work hours. These responsibilities might include talking with doctors, coordinating transportation, setting up appointments, communicating with Care Circle members, helping with emergencies, or checking on a care recipient. Juggling roles requires mental and emotional energy — both work and caregiving priorities can quickly change.

Presenteeism defines employees who are physically present for a job but cannot perform all their required duties because of illness, injury, or a personal situation. Absenteeism defines employees unable to present themselves for work. Caregivers often struggle with being both present and absent and, as a result, experience stress and feelings of guilt.

*No matter how much you do, you might feel like there's never enough time at home or work. You might be driven to compensate for lost productivity by taking work home.*

If your coworkers aren't aware of your situation, they might start treating you differently. You might feel worried about not contributing enough or your work isn't satisfactory.

Caregivers might even fear they're at risk of being fired.

But here's the hopeful news: Although every workplace differs, many employers share the caregiving experience. Some of your colleagues might even be navigating the same challenges simultaneously. Millions of people are caregivers, so remember you're not alone. Although it is never easy, there are ways to alleviate the struggle.

- **Emotionally and psychologically, accept that you can't do everything.** Have an honest discussion with yourself about what you can and cannot do. Don't overestimate your energy. Be conservative with your estimations. It's better to be surprised by what you can do than to be disappointed and embarrassed about what you thought you could do.
- **Be honest with your employer and colleagues.** Admit that you need help to handle your usual workload and accept help from people willing to assist. Make it clear that you have kept sight of work requirements.

- **Commit to less.** It's better to promise less and deliver what you said you would than to overpromise and miss the mark. If you are clear about how much you can contribute at work, you can look your colleagues in the eye at the end of the day. For the overachievers, setting boundaries will be especially difficult but also rewarding.
- **Inform your coworkers.** Provide enough information so there are no surprises if you need to take leave or management makes accommodations for your situation. Details need not be shared; you are entitled to privacy and confidentiality. You might say something as simple as "My father just had surgery. I'm his primary caregiver, and I'll be working remotely to help with his care."
- **Find a community.** In an ideal situation, you will have friends at work with whom you can be honest and vulnerable—people who will listen and support you even on the worst of days. Talking to coworkers feels different than talking with managers. Many caregivers feel alone at work, wishing someone could see and understand their struggle and step up to help.
- **Seek a support group.** Many caregivers want to talk openly about how draining it is to care for an adult, which is very different than caring for children. As such, finding coworkers, professional friends, or a support group comfortable with honesty and exploring difficult truths is important.
- **Be realistic.** Many caregivers will have to accept that there are moments in their careers when it's necessary to slow down. Some caregivers will have to look at other employment options. Many consider stepping into a less demanding position or contract work. Explore alternatives. But if you leave or change your job, understand the ramifications of forfeiting or changing health care benefits and retirement.

### Activity: What Do You Need?

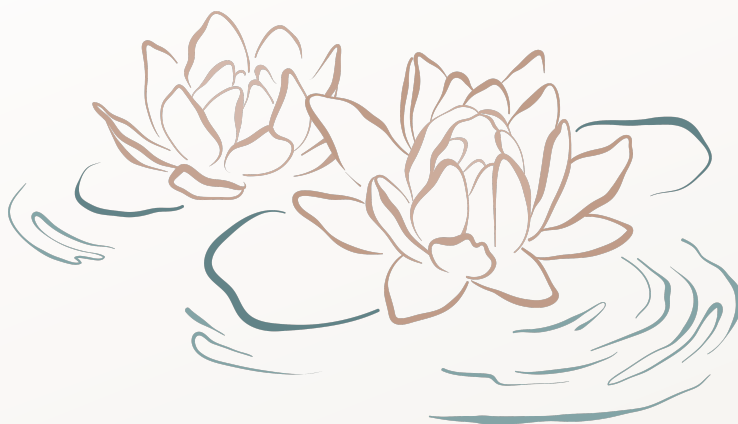
Make a list of the workplace accommodations that might help when your caregiving situation becomes challenging. From there, ask yourself the following:

1. What are the benefits and drawbacks of each accommodation?
2. Are some accommodations harder to ask for? Why?
3. Do emotional obstacles like embarrassment and guilt or workplace culture make it difficult to advocate for yourself?

When you've thought through your list, decide which accommodations you feel comfortable asking for, and make a plan to share those with your manager.

# Resilience

This is hard. We can help.



## How to Cope With the Toll of Caregiving

*Caregiving can have a significant toll on your emotional health.* You can experience many positive feelings: gratitude, confidence, accomplishment, and purpose. It can be rewarding to use your skills, strengths, and abilities to give back, and you'll strengthen your connection to your care recipient. You may deepen existing relationships, make new friendships, become part of new communities, and play a central role in bringing people together.

You're also likely to experience overwhelming negative emotions: fear, exhaustion, resentment, loneliness, hopelessness, guilt, confusion, and anger. Caregiving might keep you from sleeping, and there could be moments of frightening insecurity.

Caregiving can be as time-consuming as a full-time job. According to a study by Cambria Health solutions titled "[Wired for Care: The New Face of Caregiving in America](https://www.cambriahealth.com/sites/default/files/cambria-files/resources/Cambria%20Wired%20for%20Care%20Whitepaper.pdf)" (<https://www.cambriahealth.com/sites/default/files/cambria-files/resources/Cambria%20Wired%20for%20Care%20Whitepaper.pdf>), caregivers on average spend 32 hours a week supporting a care recipient. Further, 76 percent report canceling or delaying a life event due to caregiving responsibilities, and 1 in 5 indicate difficulty caring for themselves while caring for others.

Caregivers often lose their sense of self. Important things they enjoy may be sidelined when caregiving responsibilities take priority. As a result, essential parts of a caregiver's identity can fade into the background. Self-care can play a critical role in preserving balance in a caregiver's life.

### **What is self-care?**

Self-care is a term that has made its way into mainstream culture in recent years. It reduces stress and anxiety, improves physical health, and even enhances relationships.

But often, the things we view as self-care are what we already know we want to or should be doing. Sometimes, we didn't quite get to do these things even before we became caregivers.

You might know the airplane analogy of self-care: "Please secure the oxygen mask over your own mouth and nose before assisting others." You have to take care of yourself before caring for someone else. Just remember, self-care is not selfish.

Remember that you should enjoy self-care. It should also give you energy, moments of peace, or activities you look forward to. It shouldn't be another thing on your to-do list that you'll feel guilty about not doing.

Small acts of self-care will create momentum. One coffee date with a friend makes it easier to plan another outing. Twenty minutes with a good book might encourage you to make more time to read.

Be intentional. If you don't plan, schedule, and protect it, self-care isn't likely to happen. Block time off in your calendar. Tell people about your plans so they can help hold you accountable. Or, if you're reluctant to take time to yourself, tell people you have an "appointment" or a "meeting" when they ask you for that time. Don't let anything get in the way except true emergencies.



## Getting Professional Help

Being a caregiver is likely one of the most challenging things you will do in life. If you are overwhelmed by stress, anger, fear, sadness, or feel out of control, remember those emotions are normal.

Caregiving is complicated, as many responsibilities are piled on top of the emotions that come with the task. Professionals are trained to help you deal with the full spectrum of feelings.

Therapy and counseling are seen as normal outlets – as accepted today as walking, meditating, and eating healthy food. If you've never spoken with a therapist, here's an article by Joseph Rauch that may help you understand what to expect: "[What I Wish Someone Had Told Me About How Therapy Actually Works.](https://www.talkspace.com/blog/what-i-wish-someone-had-told-me-about-how-therapy-actually-works/)" (<https://www.talkspace.com/blog/what-i-wish-someone-had-told-me-about-how-therapy-actually-works/>)

Sometimes, however, the feeling of being overwhelmed may seem too much to endure, and you may need to seek additional support.

Please reach out for professional help when:

- You are frequently physically ill.
- You fight with friends and family.
- You struggle to take care of yourself.
- Your depression worsens and leaves you feeling hopeless.

And, seek immediate help if:

- You think about hurting yourself.
- You think about hurting others.
- You're depending on alcohol or drugs.

*If you or someone you know is at risk of harming themselves or others, call 911 or go to the emergency room. For non-emergency assistance, contact the National Suicide Prevention Lifeline at 988 or visit [www.suicidepreventionlifeline.org](http://www.suicidepreventionlifeline.org).*

### Resources

[Psychology Today's Find a Therapist search tool](https://www.psychologytoday.com/us/therapists) (<https://www.psychologytoday.com/us/therapists>)

## Settling In

When it's a marathon and not a sprint.



## 5 Critical Legal Documents for Caregivers

Imagine this scenario: Your parent is admitted to the hospital following a health crisis and had not previously outlined preferences or appointed someone to make decisions on their behalf. Suddenly, you and your family are grappling with tremendous uncertainty around desired medical care, finances, and how to proceed in an already emotional situation.

Unfortunately, stories like this are far too familiar when legal preparation is not prioritized. As a caregiver, securing proper legal documentation is one of the most impactful ways to advocate for a care recipient's dignity and stated wishes. A survey from senior living referral service Caring.com showed that 67% of American adults do not have an up-to-date will or documented end-of-life wishes. Lack of legal preparedness often leads to avoidable family conflicts and added emotional turbulence during difficult times.

Here, we'll address **five critical documents**, including steps to begin legal caregiving planning today.

- 1. Last Will and Testament:** This document specifies how a person's assets, property, and remaining estate should be distributed after they pass away. An updated will provides invaluable clarity by ensuring one's final wishes are properly documented and executed.
  - Discuss the person's intentions for distributing assets and who should be named executor(s).
- 2. Trusts:** A trust legally transfers assets such as bank accounts, property, and valuables to be managed by an appointed trustee for a person's future benefit or the benefit of other designated beneficiaries. Trusts can be established while alive (living trusts) or upon death as instructed via will (testamentary).
  - [Consult an estate attorney](https://www.naepc.org/designations/estate-planners/search#spec/All) (https://www.naepc.org/designations/estate-planners/search#spec/All) to discuss the best type of trust for your situation.
- 3. Power of Attorney:** Granting power of attorney allows a person to appoint someone trusted to make legally binding decisions on their behalf if they become incapacitated. Such determinations would relate to finances, care, and living situations.
  - [Read more about powers of attorney](https://www.caringinfo.org/planning/advance-directives/power-of-attorney-and-caregiving/#:~:text=Powers%20of%20Attorney%20may%20be,from%20Financial%20Powers%20of%20Attorney.) (https://www.caringinfo.org/planning/advance-directives/power-of-attorney-and-caregiving/#:~:text=Powers%20of%20Attorney%20may%20be,from%20Financial%20Powers%20of%20Attorney.) and determine which type might be most relevant to your circumstances.
- 4. Advance Healthcare Directive:** An advance directive outlines a person's preferences for future

medical treatment and end-of-life care if they cannot make decisions themselves. This crucial document offers guidance for caregivers and providers.

- Talk with the care recipient and their doctors about treatment preferences, documenting conversations.

**5. Living Will:** Similar to an advance directive, a living will more explicitly details the life-prolonging medical treatments and interventions a person would accept or reject in life-threatening situations.

- Discuss potential interventions like CPR, intubation, and artificial nutrition.

### Preparing for challenging conversations

Introducing legal stuff can create hurdles and difficult conversations. Here are some common reactions, along with guidance for navigating communication:

*“What if my relative doesn't want to discuss these topics?”*

- Approach conversations slowly and with empathy. Suggest that documenting wishes legally lifts future burdens and is an act of respect. Consider involving a neutral, trusted third party.

*“How can I get reluctant family members on board?”*

- You are the designated advocate for upholding a relative's autonomy, not for making unilateral decisions. Gently remind those involved of your role's boundaries, which should be documented.

*“I'm worried about the costs involved.”*

- Many low-cost or free legal aid resources exist, especially for seniors and disabled individuals. [Local bar associations](https://www.americanbar.org/groups/legal_services/flh-home/flh-bar-directories-and-lawyer-finders/) (https://www.americanbar.org/groups/legal\_services/flh-home/flh-bar-directories-and-lawyer-finders/) and [nonprofits](https://www.lawhelp.org/) (https://www.lawhelp.org/) can connect you with affordable options and financial assistance programs.

### Your efforts are significant

While tending to legal documents is undoubtedly demanding, understand it as an empowered, selfless act. You are fulfilling another's wishes according to their values, a precious gift.

Along this careful planning journey, remember you have the strength and support to be an exceptional advocate. Seeking help and addressing challenges creates a lasting legacy of honoring one's voice.

Explore the [National Institute on Aging's advance care planning resources](https://www.nia.nih.gov/health/advance-care-planning) (https://www.nia.nih.gov/health/advance-care-planning) for detailed guidance.

## Pivoting

Preparing and transitioning for the end of your care recipient's life.



### Is Home Care the Right Choice?

Home care is an increasingly available option thanks to medical advancements, better technology, and portable equipment. The advantages? Treatment in the comfort of one's own home often comes at a competitive price to a hospital or care facility, delivers the security of familiar surroundings, and can feel more consistent with the care recipient.

But there are challenges. These challenges include the increased pressure and responsibility on caregivers to understand technology procedures and equipment, pressure to consistently monitor symptoms and conditions, and managing complicated medication routines. For this reason, health professionals are almost always involved in the initial home setup – providing instruction, resources, and support.

As an at-home caregiver, you'll help your care recipient with many tasks you may never have expected to perform. A study by the [Home Alone Alliance](https://www.aarp.org/content/dam/aarp/ppi/2019/04/home-alone-revisited-family-caregivers-providing-complex-care.pdf) (<https://www.aarp.org/content/dam/aarp/ppi/2019/04/home-alone-revisited-family-caregivers-providing-complex-care.pdf>) found that at-home caregivers can be largely responsible for learning how to perform medical/nursing tasks, even complex ones.

Such tasks include:

- Managing medications (preventing mix-ups, staying on schedule, tracking prescriptions and paperwork)
- Assisting with mobility devices
- Preparing special diets
- Performing wound care
- Using monitors
- Operating medical equipment like ventilators, feeding equipment, and dialysis
- Helping with incontinence (losing bladder or bowel control), catheter care, ostomy care, and giving enemas
- Giving intravenous fluids (IV) and medications
- Managing side effects
- Tracking the progress of treatments
- Feeding tubes
- Breathing treatments

While it's always best to consult with medical professionals, several organizations offer helpful video series to refine your skills:

- The American Cancer Society's [Caregiver Support Video Series](https://www.cancer.org/cancer/caregivers/caregiver-support-videos.html) (https://www.cancer.org/cancer/caregivers/caregiver-support-videos.html) provides educational support to caregivers as they assist with the everyday needs of cancer patients and practice self-care techniques to maintain their own well-being.
- The Caregiver Action Network presents [instructional videos](https://caregiveraction.org/resources/instructional-caregiver-videos) (https://caregiveraction.org/resources/instructional-caregiver-videos) for basic caregiving needs, including measuring vital signs, range of motion exercises, bathing assistance, turning an elder in bed, and helpful products for toileting and incontinence.
- mmLearn.org's mission is to improve the quality of care and life for older adults by providing caregiver training and education. Access their video library from the website's "[Caregiver Videos](https://training.mmlearn.org/caregiver-training-videos)" (https://training.mmlearn.org/caregiver-training-videos) drop-down menu.
- UCLA Alzheimer's and Dementia Care [training videos](https://www.uclahealth.org/dementia/caregiver-education-videos) (https://www.uclahealth.org/dementia/caregiver-education-videos) focus on practical tools for understanding behaviors and creating a safe and comfortable environment for both care recipient and caregiver.
- AARP's website is home to [over 200 family caregiving videos](https://videos.aarp.org/category/videos/family-caregiving?page=0) (https://videos.aarp.org/category/videos/family-caregiving?page=0).

# Resolution and Meaning

Picking up after your care recipient dies.





## Preparing Yourself

If you've been a caregiver, especially for a long time, you're likely exhausted — physically, mentally, emotionally, spiritually. Even though the passing of your care recipient may be expected, you might still find yourself in shock.

*You'll need to do things you may have never done before.* Use the following to help prepare and manage those initial hours and days.

- **Take your time.** When death is expected, it's possible you won't need to call anyone right away. You might want to spend time with your care recipient. You might want to sleep. You might want to take a walk. *(If you're reading this ahead of time, ask if Care Circle members wish to be notified immediately if your caree passes during the night.)*
- **Notify family.** Call in your Care Circle. Contact a spiritual leader as needed to enact cultural or religious traditions to help ease the passing. Determine who should view the care recipient's body before it is removed.
- **Gather yourself, get organized.** If you can, take a moment to think about what the coming days will bring. Make a list of what you'll have to do and who will help. Prioritize tasks, ruling out what isn't an immediate need.
- **Be ready to delegate.** Many will likely say, "Let me know what I can do to help." Suggestions include taking care of children or pets, managing food, and making phone calls.

Though it will be hard, and you may feel overwhelmed, it will be more important than ever to prioritize moments of self-care, including rest and quiet. Take a deep breath. You will get through this.

### Moving Forward

*Grieving never ends — it just changes form.* You experience new feelings. You find more ways to cope. Sometimes, the pain is soft, and you can focus on good memories, but other times, you'll feel deep pain that you might have expected to go away over time. Still, you'll move forward, learning and finding new meaning even as your loss becomes more distant. You'll have a deepened understanding of and compassion for others who experience loss.

## Other Caregiver Support Resources We Love

### [Confessions of a Reluctant Caregiver Podcast](#)

“We combine the power of relationships and technology to relate, educate, inspire, and provide resources to individuals of all ages, who are desperately seeking how to support their loved one while also maintaining their sense of self and sanity.”

### [Happy Healthy Caregiver Blog](#)

“Elizabeth Miller is a Certified Caregiving Consultant, Certified Senior Advisor, member of the Whole Care Network Speakers Bureau, facilitator of in-person and virtual support groups, and a working family caregiver.”

### [Aidaly](#)

“Aidaly provides family caregivers with the support, training, and compensation they need to deliver high-quality care in the home.”

### [NaborForce](#)

“We match older adults who need a little help and kindness with Nabors eager to provide it, strengthening the communities we serve.”

### [CareForward Platform](#)

“Harnessing the power of technology, CareForward connects those in need with community members who donate Time, Talent, or Resources.”

## In Closing

As you move forward in your caregiving experience, remember that this guide is here for you whenever you need it. Lean on these resources, take things one step at a time, and trust in your resilience. At Caregiver, we're honored to support you and hope this guide brings you comfort, strength, and the reminder that you're never alone.

### Home

<https://www.caregiven.com/>

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