IMERMAN ANGELS

Cancer Caregiver Companion

How to Take Care of Yourself When You're Caring for Others



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"What do caregivers do? The answer is... everything."

– **Allison J. Applebaum, PhD** in her book ***Stand by Me: A Guide to Navigating Modern, Meaningful Caregiving***

A Letter from Imerman Angels Executive Director



Dear Caregivers,

At Imerman Angels, we believe that no one should face cancer alone. For 20 years, we have connected people impacted by cancer, including caregivers, with someone who has been there before – someone who understands the questions, emotions, challenges, and moments that can be difficult to explain to anyone else. We do this by providing people with a free trained peer mentor, called a Mentor Angel.

We created this Cancer Caregiver Companion to help you navigate the caregiving experience with practical information, resources, and guidance from people who have been through it. Just as importantly, we want to remind you that you matter, too. Taking care of yourself is not selfish or a distraction from caring for someone you love; it is essential.

As a cancer caregiver, you may find yourself facing decisions, navigating an unfamiliar healthcare system, offering emotional support, and trying to keep everyday life moving, all while managing your own fears and feelings. There is no single "right" way to be a cancer caregiver, and you don't have to have all the answers. This Cancer Caregiver Companion is not intended to be another list of things you should be doing. It is meant to help you feel more prepared, empowered, and less alone.

On a personal note, this Cancer Caregiver Companion is the resource I wish *I* had when I became a caregiver. Supporting my twin brother through his cancer diagnosis, I experienced firsthand the challenges that caregivers face – and the lack of resources available to support us.

As Rosalynn Carter said, "There are only four kinds of people in the world – those who have been caregivers, those who are currently caregivers, those who will be caregivers, and those who will need caregivers." While no one plans to be a caregiver, this is a role we will all likely take on in some form within our lifetimes. I hope this Cancer Caregiver Companion provides the comfort, hope, and support you need, and serves as a reminder that your experiences are valid, your needs matter, and even on your most difficult days, you're not alone – others have walked this path before you and we're here to light the way.

Warmly,



Stephanie Lieber
Executive Director

Chapter 1: We're Here to Support You

Caregiving is one of the most difficult roles anyone can ever hold. If you're a caregiver, you likely know all too well that there isn't a lot of support available for caregivers, and resources can be very hard to find – especially when much of your time and energy is already devoted to caring for your loved one.

That's why we created this **Cancer Caregiver Companion** – to help and support you through the immense difficulties that come with being a caregiver.

Imerman Angels: Who We Are and What We Do

Imerman Angels is a nonprofit organization founded on the belief that no one who's been impacted by cancer should have to go through it alone. Our mission is to provide comfort and understanding for all cancer fighters, survivors, previvors (people with a hereditary genetic mutation or other inherited risk factor that increases their likelihood of developing cancer), and **caregivers** through a personalized, one-on-one connection with someone who has been there – a peer mentor, called a **Mentor Angel**.

Caregiving can be rewarding, but it can also be incredibly taxing. A Mentor Angel is a trusted confidant you can turn to during all the highs and lows, and whose presence is a reminder that you're not alone.

Our peer mentorship matching program is **free** and available to people residing anywhere in the world. Peer mentorship is a form of psychosocial support.

What Is Psychosocial Support?

Psychosocial support is defined by the National Cancer Institute as "support given to help meet the mental, emotional, social, and



spiritual needs of patients and their families." For example, psychosocial support for patients, survivors, previvors, and caregivers can include therapy and mental health counseling, support groups, one-on-one peer mentorship, and spiritual guidance and support (e.g., from a religious leader, faith-based group, or non-denominational hospital chaplain).

ABOUT THIS GUIDEBOOK

We know that you're busy juggling caregiving along with multiple other responsibilities and are often overwhelmed. You might not have the time or energy to do extensive online research to find helpful resources, figure out how to navigate the complexities of the healthcare system, take care of your loved one, *and* try to find a minute in the day to attend to your own needs!

This guidebook is comprehensive – yet manageable and easy to navigate – so it helps ease some of the load that you're carrying and doesn't add to your overwhelm. We designed it so you can read it from cover to cover if you'd like, or just flip to the section you need to reference in the moment.

This guidebook will:

- **Provide a roadmap**. Unfortunately, caregiving doesn't come with a how-to manual, and navigating a cancer diagnosis and treatment alongside your loved one is filled with unknowns and uncertainty. We've found that knowing what to expect can help ease some of the burdens and prepare you for the difficulties that come with this role. In this guidebook, we'll take you through common caregiving scenarios, what to expect at each phase, and how to handle the challenges that may arise along the way.
- **Help you feel seen, acknowledged, and valued.** As caregivers, we often feel unseen, unheard, and unappreciated. It can sometimes be a thankless role, where our needs are continually put on the backburner. We know firsthand how hard caregiving can be, and how isolating it is when people in our lives don't understand what we're going through. We want to provide a space that acknowledges and values everything you do.
- **Give you actionable tips, tools, and resources.** We did the research so you don't have to! Throughout these pages you'll find practical tips and tools for common caregiver challenges. Toward the end, we've included printable checklists and a curated list of our favorite resources for caregivers.

What Makes This Guidebook Different

We saw that something was missing from the caregiver support space, so we created this guidebook to fill that gap. Here's why this guide is different from other caregiver resources.

1. It's for YOU.

Most caregiver resources focus on how to support the person who's been diagnosed with cancer. That's important – and necessary – but caregivers need support, too. This guidebook is all about addressing *your* needs and supporting *you*.

2. It focuses on psychosocial needs.

As a caregiver, there are countless logistics to manage, and there are several resources available to help you do this. What we *didn't* see were resources dedicated to caregivers' psychological and emotional needs – so we created one.

3. It addresses the challenges... and makes space for the benefits.

The challenges of caregiving are immense and the burdens are heavy; we don't want to minimize that. Caregivers can be at risk for burnout and serious mental and physical health conditions. We'll provide strategies to help mitigate these risks.

But we've also found that it's helpful to examine the benefits that can come with caregiving – from developing resilience and strength, to learning critical life skills, to gaining meaning and purpose. Acknowledging your growth, and recognizing the moments of joy and connection with your loved one, can help bolster you in good times and sustain you through difficulty.

4. It's hands on — but only if you want it to be.

Everyone likes to read and absorb content differently. Some people prefer to roll up their sleeves, dig in, and mark up the margins, while for others, simply reading a guidebook is more than enough.

If you're the kind of person who finds it helpful to write things down, we've included spaces for notes throughout these pages, as well as printable worksheets at the end. If you feel like written activities are extra work that you have

no desire to take on, then by all means, skip them!

This is why we've deliberately called the questions at the end of each chapter *Reflection Prompts* instead of *Journaling Prompts*; they're gentle suggestions for reflection, with no pressure to write anything down – especially if putting pen to paper feels overwhelming and not helpful.

5. It gives you an introduction to what having a Mentor Angel is like.

If you're not yet familiar with Imerman Angels and our work and haven't had a Mentor Angel, you may not know much about peer mentorship and what to expect. To introduce you to peer mentorship and give you a feel for what it's like to have a Mentor Angel in your corner, we've included "Notes from a Mentor Angel" throughout this guide.

These notes are words of encouragement from our Caregiver Mentor Angels – what they might share with someone in your place and how they provide comfort and support to their Mentees. Consider them a glimpse into the understanding and connection that can come from someone who has walked a similar path, and a taste of what you can expect if you're matched with your own Mentor Angel.

Expert Insights and Lived Experience

This guide was created with caregivers and your experiences and needs at the center. We conducted extensive research, including:

- Interviewing several leading caregiving experts with experience across a range of different populations
- Facilitating a Focus Group made up of Caregiver Mentor Angels
- Soliciting additional Caregiver Mentor Angel input
- Reaching out to members of our Wellness and Medical Advisory Board
- Holding in-depth interviews with our Co-Advisors and Lead Contributors:
  - Caregiving Expert **Allison J. Applebaum, PhD**, Professor of Geriatrics and Palliative Medicine and Director of the Steven S. Elbaum Family Center for Caregiving at the Icahn School of Medicine at Mount Sinai, Author of *Stand By Me: A Guide to Navigating Modern, Meaningful Caregiving,* and Caregiver
  - Lived Experience Expert **Jemma Cabral**, 2x Cancer Survivor, Caregiver, American Cancer Society Community Research Partner, and Imerman Angels Cancer Survivor and Caregiver Mentor Angel

See our Contributors section on page 61 for a full list of contributors.

Reflection Prompt:

What made you pick up this guidebook? What are you hoping to get out of it?

NOTES

Chapter 2: What Is a Caregiver, Exactly?



A **caregiver** is a person who provides long- or short-term care to someone who needs assistance due to an injury, disability, or illness – in this case, cancer.

Broadly, caregiving falls into two main categories.

- **Professional (or Paid) Caregivers:** Doctors and nurses; social workers; direct care workers who provide assistance in the home, such as home health aides, certified nursing assistants, and personal care aides; and more.
- **Family (or Unpaid) Caregivers:** This term is a little misleading because you don't actually have to be related to the person you're caring for; it can include parents, siblings, children, spouses and partners – and also friends, roommates, neighbors, and community members, among others. *If you picked up this guidebook, you're likely a family caregiver. For the purposes of this guide, this is the type of caregiver we will be focusing on.*

Caregivers Can Also Be Called...

It gets more complicated, though, because several different terms are often used interchangeably to describe caregivers. In addition to the word "caregiver," you may have heard your role referred to as **care partner**, **carer**, or **co-survivor**, among others.

You may also hear different terms used to refer to the person you're caring for. This could include **patient**, **survivor**, or **care partner or recipient**, among others.

Some people relate to certain terms more than others, or find some of the terminology upsetting and triggering. There are no right or wrong terms here and we encourage you to use whatever language is most helpful to you.

And Caregiving Can Look Like...

As mentioned, caregiving can encompass a wide range of different types of relationships with the person you're caring for, and a multitude of various scenarios. For example, caregiving can look like providing care for a:

- Parent
- Child
- Sibling
- Spouse or romantic partner
- Friend
- Neighbor
- Roommate
- Someone you are estranged from

You can be a:

- **Primary Caregiver:** Person who holds the main responsibility for overseeing, delivering, organizing, and managing care day to day.
- **Secondary Caregiver:** Individual who provides supplemental help with specific tasks, is available for backup assistance or to cover for the primary caregiver when needed, and/or supports the primary caregiver with their needs.
- **Part of an Extended Caregiving Network:** One of a group of people involved in caring for someone through various tasks and actions, such as being part of a Meal Train (dropping off prepared meals); helping research diagnoses, doctors, and treatment options; setting up and managing a GoFundMe; attending chemotherapy appointments; driving someone home from surgery; and more.
- **Long-Distance Caregiver:** There are unique challenges when you do not live near the person you are caring for. Some include not being able to be as involved as you'd like, financial and logistical difficulties of traveling back and forth, and considerations about relocating yourself or your care partner to be closer together.
- **Bereaved Caregiver:** Someone who has lost the person they were caring for through death, and is now navigating the dual transition of grief and the loss of their caregiving role.

Complexities of Being a Cancer Caregiver

Being a caregiver is undoubtedly difficult regardless of the illness, physical impairments, or mental health challenges of your loved one. But certain circumstances that come with a cancer diagnosis can make cancer caregiving uniquely challenging. Here are a few of the factors that can contribute to the complexities of being a cancer caregiver specifically.

- **Learning complicated terminology.** Understanding oncology appointments, test results, treatment options, and more requires a whole new vocabulary. In order to make treatment decisions and advocate for your care partner, you have to very quickly get up to speed on unfamiliar scientific terminology and medical jargon.
- **Performing medical and nursing tasks.** According to an article from Fred Hutch Cancer Center, cancer caregivers commonly have to handle intensive medical tasks at home, such as cleaning and caring for wounds, giving injections, and administering IVs. Cancer caregivers often have to learn these skills with little to no training.
- **Managing heavy at-home care burden.** In addition to the complex medical tasks listed above, cancer caregivers often have to manage multiple medications that need to be taken at different intervals, monitor for side effects, and frequently communicate with healthcare teams.
- **Coping with unpredictability.** From dealing with looming worries of cancer recurrence to uncertainties about treatment effectiveness and the severity of side effects, being a cancer caregiver is full of unknowns and unpredictability. The hypervigilance and adaptability often required can make it difficult to maintain a routine or sense of normalcy and can be mentally and emotionally taxing.

Caregiving for Previvors

Previvors (people with a hereditary genetic mutation or other inherited risk factor that increases their likelihood of developing cancer) and their caregivers can sometimes get left out of these conversations. If you are supporting a previvor who's navigating increased cancer risk, you are a caregiver, too. For parents of previvors, the experience can carry an added layer of worry, protectiveness, and uncertainty.

Previvors face different, but still difficult, challenges from people who've been diagnosed with cancer. As a caregiver to a previvor, these are some experiences you may

be supporting them through.

- The need to get cancer screenings more frequently or beginning at a younger age due to their heightened cancer risk
- Coping with worry and anxiety while waiting for these test results
- Living with the fear of developing cancer
- Making decisions about potential risk-reducing surgeries, fertility preservation, and/or family building
- Recovering from risk-reducing surgeries, which, for caregivers, can mean performing medical and nursing tasks such as helping with wound care and managing post-op medication

In addition, you might also be navigating your own complicated emotions. For example, it's common for relatives of people with hereditary cancer-related genetic mutations to feel guilty if they *don't* have the mutation.

There are fewer support resources for previvors than there are for people who've been diagnosed with cancer, and as a caregiver for a previvor, you'll likely have fewer support resources for yourself, too. While there are support groups for previvor caregivers, the options tend to be limited.

At Imerman Angels, we provide **Mentor Angels** for caregivers of previvors, so you'll be connected with a peer mentor who understands your specific, unique challenges and experiences.

Additional Barriers and Challenges

While there are many commonalities across the caregiver experience, and some aspects of this role can be universal, we also want to acknowledge important differences – people in marginalized communities can face additional barriers, burdens, and difficulties, such as:

- **Overt discrimination**, or obvious, visible acts that deny opportunities and/or fair, equitable treatment to people based on their age; race; gender, gender identity, or sexual orientation; physical or mental abilities; or other factors
- **Implicit bias**, prejudices that are so ingrained that the person holding these beliefs isn't even aware of them
- **Microaggressions**, or insulting comments or actions that subtly and sometimes unintentionally express prejudice toward a member of a marginalized group
- Cultural norms, stigmas, pressures, and expectations
- Less access to healthcare, supportive resources, and health insurance
- Financial, housing, work, and/or food insecurity

This list is not exhaustive, but a few examples of populations that may face these and other challenges include:

- Black, Indigenous, and People of Color (BIPOC)
- LGBTQIA+
- Pediatric cancer patients
- Adolescent and Young Adults (AYAs)
- Older adults
- Individuals with physical or mental disabilities
- People who live in remote, rural areas
- Low-income individuals and families
- Non-native English speakers

The burden of caregiving can be immense, and for those who face additional burdens, there is an even greater need for resources and support – but, paradoxically, those resources and support may be harder to find and access. In our Recommended Resources section at the end, we've included resources designed to address some of the specific needs of marginalized individuals and communities.

Why Defining What a Caregiver Is Matters

We've found that many people are taking on caregiving responsibilities for a loved one, but don't know that they're a caregiver. And some people don't consider themselves caregivers because they are just doing what they've always done – helping out. Or maybe they don't fall into the "typical" caregiver image of a spouse caring for their partner, for example, so don't realize that the term "caregiver" also applies to them.

But if you are performing any kind of caregiving responsibilities, it can be beneficial to know and acknowledge, at least to yourself, that you're a caregiver. Here's why:

- Giving a name to your role – *caregiver* – can be very helpful in terms of validating your experiences, especially when you're struggling with overwhelm and burnout. For example, if you feel exhausted and stretched too thin, knowing that this experience is common for caregivers helps make it less personal; there's nothing wrong with *you*, it's just part of the caregiving role.
- In addition to patient services for the person diagnosed with cancer, there are many free resources and support services available to caregivers – **and you qualify for them!** Some options we've seen include caregiver support groups, free virtual or in-person yoga classes for patients and their caregivers, free therapy with an oncology social worker at a nonprofit cancer organization, and/or peer support from a Mentor Angel at Imerman Angels. We recommend finding resources that meet your needs and taking advantage of as many as you find helpful.
- When you know that you're a caregiver, you can discover that you are actually a part of an entire *community* of caregivers – and that community is able to help you with one of the most difficult caregiving challenges there is: Isolation. Tap into this community by connecting with other caregivers with similar experiences through in-person or online support groups, one-on-one peer support, and more.

Reflection Prompt:

Do you relate to the role of "caregiver"? Why or why not?

NOTES

Chapter 3: Caregiver Roadmap

The stages of caregiving can be tricky to define – they usually don't have a neat beginning and ending and can happen out of order or overlap, and everyone's experiences are going to be different. However, it can be helpful to have a general idea of what to expect at different points in the caregiving journey to help lessen fear and anxiety.

Below, we've listed common stages of caregiving, what to expect at each phase, and tips from experts and caregivers to help you through each part of the journey. Note that this is a general guideline; these stages don't always happen sequentially and might not exactly describe your personal experience.

STAGES OF CAREGIVING

1. Stepping Into the Role

What to Expect

This phase often starts before the moment of a cancer diagnosis, in the days, weeks, months, or years leading up to it. During this stage, your loved one may be experiencing symptoms, going to doctor appointments, getting medical tests, and waiting for results.

This then leads into finding an oncologist and/or assembling an oncology care team, possibly seeking a second opinion, and deciding on a treatment plan. You're likely overwhelmed; when cancer suddenly crashes into your life, you're inundated with new information and faced with countless decisions to make, one right after the other.

You're also navigating a very steep learning curve as you're faced with unfamiliar scientific terminology and medical jargon.

Overall, this is a time filled with unknowns, uncertainty, fear, anxiety, stress, and sadness.

Your loved one's diagnosis can also bring up **mixed emotions**: You can love them and be upset about their diagnosis, and at the same time feel resentful about having to take on the caregiving role and angry about any goals, activities, and plans that you'll have to give up to take care of them.

While caregivers may be caught off guard by these confusing, conflicting emotions, and then judge themselves for feeling anything besides love for their care partner, please know that **this is very common** and many people experience it. Try to be gentle and not judge yourself. A cancer diagnosis turns the lives of everyone involved upside down – and that includes the caregiver's life, too. You are human, and it's totally normal to feel sadness, loss, and resentment over the ways your life is going to change.

What Can Help

Establish caregiving roles and responsibilities early on. This is a delicate balance. On one hand, you want to be sensitive to your care partner, let them set the pace of decisions that need to be made, and follow their lead. Caregivers in our community say it's important to be patient and available to listen as your loved one processes all this new information. You don't necessarily want to burst in on Day One with a huge to-do list and a long list of plans and overwhelm them.

On the other hand, the vagueness of undefined caregiving roles can lead to confusion for the person who's been diagnosed and their caregivers. Important tasks can fall through the cracks, and resentments can develop when people are taking on more than they're able to or less than they want to without feeling like they have a say in it.

HOW DO YOU DEFINE CAREGIVING ROLES AND RESPONSIBILITIES?

To help you establish your caregiving role, and the responsibilities of others in your caregiving circle, we've put together this list of questions.

1. Who is going to be the primary caregiver?

2. Who is going to be the secondary caregiver(s)?

3. How involved will I be?

4. What responsibilities will I be handling? For example:

- Scheduling appointments
- Attending oncology appointments in person or via phone or video chat
- Driving your loved one to and from chemotherapy appointments
- Researching necessary cancer resources, medical information, and treatment options
- Managing medications and medication adherence at home
- Organizing a Meal Train
- Creating and managing a GoFundMe
- Buying groceries
- Handling childcare responsibilities
- Doing home cleaning and laundry
- Paying bills
- Filling out medical and financial paperwork
- Advocating on your loved one's behalf with health insurance companies, etc.

5. What responsibilities fall outside of what I will be doing? Who in our family, extended family, friend circle, and broader community is able to help with these tasks? *(See our "Building Your Caregiving Support System Worksheet" on page 47 for help organizing tasks that need to get done and figuring out how to delegate them.)*



Start to get support for yourself if you can. Leading up to your loved one's cancer diagnosis through receiving a diagnosis and beginning treatment is a chaotic and overwhelming time. Understandably, you may be so busy attending to your care partner's needs, learning new information, and making critical decisions, that seeking support for yourself might be the furthest thing from your mind.

However, during these early days you'll be confronted with countless logistical, mental, and emotional challenges, from working to establish caregiving roles and responsibilities to negotiating with (sometimes unhelpful) family members, to experiencing a range of complicated emotions.

It can be helpful to connect with other caregivers who've experienced what you're going through early on, whether that's through a support group, an online forum, or a peer mentor like an **Imerman Angels Mentor Angel**. This person or people can be a listening ear and a voice of comfort during dark, difficult days. They can validate and normalize what you're feeling, share their experiences, and offer guidance when needed. Crucially, they can buffer you from the isolation that often comes with caregiving right from the start, before it has a chance to take hold.

NOTE FROM A MENTOR ANGEL

I remember that first week after my loved one's diagnosis. The ground shifted under me and I was filled with a flood of emotions I wasn't ready for. If you're overwhelmed, exhausted, scared, or just don't know what to do next, please know that was my experience, too.

Take a deep breath and let your shoulders drop. You don't have to have it all figured out right now. It's okay to ask questions. And please let yourself lean on others, even if that feels hard and you're usually the one holding everything together. Having someone who's already walked this road (a Mentor Angel), someone I could ask anything without feeling judged, made all the difference for me.

As a Caregiver Mentor Angel, I am here to remind you that you are stronger than you realize. From this moment forward, you aren't alone; there's a whole community of us here to help carry the weight with you.

In your corner,

William
Caregiver Mentor Angel & Caregiver to Mother Diagnosed With Lung and Neuroendocrine Carcinoma

Mentor Angel notes have been edited for length and clarity.

2. In the Middle of Things

What to Expect

At this point, the shock of diagnosis might be wearing off and you and your loved one may be finding a regular routine of oncology appointments and learning the rhythm of when any treatment side effects hit during a given cycle.

At the same time, as the adrenaline of those early days wears off, you may find feelings of overwhelm and resentment crop up as you realize how much of your life is now occupied by caregiving and how much you've had to change or give up, whether that be time with friends and family, professional goals, a favorite workout class or hobby, or beloved plans and routines.

When your loved one is in the midst of their treatment, you may feel like there is no end in sight to your caregiving duties.

Another challenge of this phase is that your broader caregiving support network may start to dwindle. People who enthusiastically showed up to help you and your loved one when they were diagnosed may be falling away as time goes by.

What Can Help

Reassess logistical and emotional needs. Caregiving isn't a "set it and forget it" situation; it requires ongoing evaluation – and *re*evaluation. Needs and concerns, for both you and your care partner, constantly change and adjustments need to be made.

This is a good time to take stock. Create a list of *all* the tasks you need to do – both those that are caregiving-related *and* daily life tasks that have piled up because you're occupied with caregiving duties.

Then think about who in your network might be available to help and try to delegate some of your responsibilities. Having a list is helpful because then when someone says, "How can I help?" you can refer to your list and give them a task! *(See our "Building Your Caregiving Support System Worksheet" on page 47 for our template to use for this exercise.)*

You may have been in "nose-to-the-grindstone" mode when your loved one was first diagnosed, so now is also a good time to pause and consider your mental health and well-being. Experts stress the importance of seeking professional mental health support, like seeing a therapist, counselor, and/or psychiatrist if needed.

MENTAL HEALTH SUPPORT FOR CAREGIVERS: WHERE TO START

It's helpful to go to a therapist who specializes in, or at least has some experience working with, caregivers and understands the particular challenges you face. Here are some tips for finding a mental health professional with that specific expertise.

1. **Talk to your hospital's oncology social worker.** Ask if they know of any therapists with experience working with caregivers who they can refer you to. You can also ask about any community-based organizations that might offer this service for free.

2. **Search on PsychologyToday.com.** PsychologyToday.com provides a searchable therapist database, and you can set up filters to search for professionals who meet specific criteria. While there's currently not a search term for "caregiving," you can check boxes to search for therapists with experience in "chronic illness" and "cancer" and that may turn up some mental health professionals with caregiving experience.

3. **Ask other caregivers for recommendations.** The best referrals come from people with similar circumstances who've actually gone to that therapist. Just be sure to do your due diligence before starting to work with a new mental health professional. For any therapists you are considering, we suggest ensuring that they're properly licensed and credentialed, and reading any online patient reviews that are available.

Most therapists offer an initial consultation appointment for free so you can get a better sense if they're a good fit for you and your needs.

Set boundaries… and help find solutions. Many caregivers wonder, "Is it ever okay to say 'no'?"

While you want to be there for your loved one in every way you can, there may be times when saying "yes" to them is going to come at your own expense. While it's common to feel obligated to do everything that's ever asked of you – and then some! – it is okay to say "no" when you have to.

There's a bit of a caveat, though: People can experience a "no" response to their request as a personal rejection. So if you find that you're not able to perform a caregiving task for whatever reason – you can't get the day off work, you aren't able to find childcare, you have your own health emergency – our Caregiver Mentor Angels suggest a "No, but…"

What this means is that although you're not able to do something, you're not just leaving them hanging; you're going to help find someone else who can. Here are some examples of what that might look like.

"I'm sorry I won't be able to pick you up at the hospital after your surgery because I have to go on a last-minute work trip. I've called Dad and arranged for him to get you."

"My babysitter fell through this week so I can't come to your chemo appointment with you like we'd planned. Your sister said she can make it, and if there's anyone else you'd feel comfortable having there I can call around and see who's available."

"I'm really run-down and am not going to be able to fly into town to go to your oncology appointment with you. I'd love to still be able to join you by attending the appointment via FaceTime if you're okay with that."

NOTE FROM A MENTOR ANGEL

I know the mountain ahead seems impossible to climb. You are exhausted. You are fearful. You are wearily hopeful. I see you. You will make it through this. Take time each day for yourself – 10 minutes here and there. Reconnect with yourself. Breathe. Cry. Whatever helps you unload the burden you are carrying. Don't be afraid to ask for help. People want to be there for you, you need only ask. Let them help you. You can't give to anyone else when you're running on empty, so it's important you take care of yourself.

– Kayra
Caregiver Mentor Angel & Caregiver for Husband Diagnosed With Head and Neck Cancer

Mentor Angel notes have been edited for length and clarity.



3. Transition to Survivorship

What to Expect

Many caregivers and cancer survivors alike are caught off guard at this phase. You might think that when active treatment is done, there's a big, sweeping feeling of relief and joy. But in reality, it's a lot more complicated than that.

First of all, for both the caregiver and the person diagnosed with cancer, there can be a tendency to power through treatment in flight-or-flight mode: You put your head down and go from one decision, task, and appointment to the next.

It's only when treatment ends that you and your loved one have a moment to pause, and that's when the emotional impact of what you've been through tends to hit.

At this point, without the routine of medical checkups and appointments, both caregivers and survivors can experience a feeling of being lost and adrift. The absence of regular oncology appointments can also trigger fears of recurrence. What's more, the emotional impact of the transition to survivorship sometimes hits caregivers *harder* than the person diagnosed with cancer. After treatment, cancer survivors often experience an improvement in their quality of life and overall well-being. Many experience a "new lease on life" – going through cancer treatment prompts them to take stock, reprioritize, and make changes.

On the other hand, caregivers often experience a significant increase in distress, anxiety, and depression. Again, this has to do with coming out of fight-or-flight mode and finally having a moment to reflect on what you've been through. This might also be a time when you feel some of the effects of choices you had to make while caring for your loved one, such as skipping your own medical appointments or not being able to prioritize your mental health.

What Can Help

Know that what you're feeling is normal. Caregivers (and survivors, too!) are often surprised that they don't feel purely overjoyed when treatment ends. The truth is, it's very common to feel a wide range of seemingly

conflicting emotions at this point: relief and anxiety, elation and depression, excitement and exhaustion can all coexist.

Whatever you're feeling during this phase is not wrong – it's perfectly normal. And chances are, other caregivers are feeling it, too.

Connect with other caregivers. People are often blindsided by how difficult the transition to survivorship can be. Some *stop* seeking support at this point because they think the difficulties of cancer are "all in the past" or that they are no longer a caregiver once their loved one isn't in active treatment anymore.

If you've already been getting some form of psychosocial support, we recommend continuing. And if you haven't started yet, we recommend beginning. An Imerman Angels **Mentor Angel** is an option that offers a lot of flexibility – you can communicate with them as much or little as you like, and be in touch in whatever ways work for you, whether that's via email, phone, texting, or video chat.

NOTE FROM A MENTOR ANGEL

Survivorship is its own journey that friends and loved ones don't always understand, often congratulating us on the cancer being "over" and "behind us," and our loved one being "all good now."

The completion of active treatment can mean more free time, so it can be a good time to connect with other survivors and their care partners who may be more in tune with possible late effects of treatment and the stress of "scanxiety."

Though survivorship may bring its own set of challenges, the completion of active treatment is a time to celebrate! Every clean scan, every day that feels increasingly "normal," is worthy of joyful celebration.

– Emily
Caregiver Mentor Angel & Caregiver to Daughter and Husband Diagnosed With Brain Cancer

Mentor Angel notes have been edited for length and clarity.

4. Long-Term Illness and Terminal Diagnoses

What to Expect

Sometimes, there is no "end" to treatment – in cases of chronic and terminal diagnoses, treatment can extend indefinitely. There can be periods when your loved one's disease is stable, and times when the cancer and/or treatment side effects progressively get worse.

When treatment extends for years or even decades with no end in sight, it can be especially overwhelming and exhausting for caregivers. We can't stress this enough: All that responsibility for such an extended period of time can be very difficult to bear and take a tremendous toll on caregivers, physically, mentally, and emotionally.

Additionally, over time, your support network may have thinned out, and people who helped out in the beginning may have drifted away. You may have less help than you need and fewer people to rely on when you need help.

What Can Help

Seek professional help with logistics… Especially as caregiving responsibilities continue for years, and perhaps some of your initial support network has fallen away, it can be helpful to enlist professional support to assist with some of your caregiving duties – or handle them entirely from time to time so you can take a break. This is sometimes referred to as **respite care** and it can include things like hiring home health aides or certified nursing assistants who can help your loved one with **activities of daily living (ADLs)**, the routine,

necessary daily personal care tasks, such as bathing, dressing, eating, and going to the bathroom.

One drawback: This could be a significant expense and may not be financially feasible. We suggest talking to an oncology social worker at the hospital where your loved one is being treated to see what options and financial assistance may be available. Ask if there are any local organizations that provide trained caregiving volunteers who can help with personal care tasks or light cooking and cleaning.

And take advantage of any patient navigation services offered at your hospital – perhaps someone is able to help you fill out complicated financial assistance applications or understand confusing insurance statements.

...and to support your mental health. The ongoing responsibilities of caregiving can take a serious toll on your mental health – especially over a prolonged, indefinite period of time that can be filled with ups and downs and uncertainty. Needs and challenges – for you and your care partner – change over time, and it's important to periodically take stock of how you're feeling, physically and emotionally.

If you haven't already sought professional mental health support from a counselor or therapist, this may be a good time to consider it. Even if you're already participating in a support group, involved in online support forums, and/or have a peer mentor, a mental health professional can complement these other forms of support. And serious mental health concerns that interfere with your ability to function and impair your quality of life require the help of a professional.

See the "Mental Health Support for Caregivers: Where to Start" section on page 16 for guidance on how to find a therapist who meets your needs and our "Common Risks Associated With Caregiving" section on page 25 for more information on ***caregiver burnout.***

If cost is a barrier, search for mental health professionals who accept your insurance on PsychologyToday.com or contact your insurance company directly for a list of in-network therapists. Some nonprofit organizations provide a set amount of free therapy sessions with an oncology social worker for caregivers. And some therapy practices offer a need-based sliding scale payment option; try doing a Google or AI search for therapists in your area with a sliding scale.

Consider palliative care. Palliative care is often confused with hospice care but they are actually different.

Hospice care provides comfort to people with a terminal illness who are nearing end of life. Similarly, the aim of palliative care is to provide comfort and improve quality of life, through things like symptom and side effect relief; education and advocacy; social, emotional, and spiritual support; and more. But unlike hospice care, you don't have to be approaching end of life or have a terminal diagnosis to qualify. *Palliative care can begin at any point during cancer treatment from the moment of diagnosis.*

Another little-known fact: Palliative care is also available to caregivers and can help you get the support you need, from guidance on logistics to mental and emotional support.

Some examples of palliative care services might include:

- Nutritional counseling
- Exercise guidance
- Physical or occupational therapy referrals, if necessary
- Referrals to helpful support resources
- Assistance dealing with work and insurance issues and filling out forms

Talk to your loved one's care team or hospital social worker to learn more about palliative care and how it can help both your care partner and you.

NOTE FROM A MENTOR ANGEL

What you're carrying is different from the caregiving stories with a finish line – the surgery date, the end of chemo, the discharge home. Yours doesn't have that shape. It's more like walking a road in fog, where you can't see how far it goes or what's around the next bend, and you're not even sure the road has an end you'd want to reach.

On the hardest days, when the future feels unbearable to think about, it's okay to shrink your focus down to just this hour, just this task, just this moment of connection – you don't have to hold the whole unknown timeline in your hands at once. You are doing something profoundly hard, without applause, without an endpoint, and that deserves to be named and honored, not just endured quietly.

– Palash

Caregiver Mentor Angel & Caregiver to Wife Diagnosed With Lung Cancer

Mentor Angel notes have been edited for length and clarity.



5. Approaching End of Life

What to Expect

People often associate grief with something you feel *after* a significant loss, like the death of a loved one. What you may be less aware of is that there are other forms of grief caregivers experience that can be equally devastating. While everyone experiences grief differently, these are two forms that commonly affect caregivers.

Anticipatory Grief: This can happen when your loved one has cancer, and particularly a terminal diagnosis. Perhaps their disease is progressing; their symptoms, along with their quality of life, are worsening; and/or they may be approaching end of life. As their caregiver, you may imagine their future death and a time when they are no longer with you, which can bring on deep feelings of loss and sadness.

Pre-Loss Grief: This is grief about aspects of your loved one and/or your relationship with them that have changed as a result of their illness. This can be things like your care partner no longer being able to be as self-sufficient as they once were or having difficulty with activities of daily living, like getting around, dressing themself, and going to the bathroom independently. It can also include changes to your loved one's mental capacity; cancer and some treatments can have cognitive impacts, affecting attention, concentration, and memory, to name a few. So your loved one may not be as articulate as they once were, or become more forgetful.

In addition to your loved one changing, the relationship between the two of you might be completely upended. For instance, you've been used to your parent taking care of you for your entire life, but now you might find yourself needing to assist *them* with their basic needs, like feeding and bathing them. Or your day-to-day routine with your spouse is now defined by caregiving responsibilities and looks nothing like the relationship you had with them before their diagnosis, when friendship and romance were also part of the equation. These are all tremendous losses that deserve to be acknowledged.

What Can Help

Discuss your loved one's healthcare, financial, and end-of-life wishes. Facing mortality – your own or that of a loved one – is incredibly difficult. Most people *don't* want to face it, which is why it's common to go into denial when the end of a care partner's life is approaching and avoid these important conversations. Who wants to accept and face this devastating reality?

But there's a powerful reason to push through denial and discomfort and have these difficult conversations: Minimizing regret. Many caregivers regret *not* having these conversations while their loved one was still alive and would give anything to go back in time and do it over.

Additionally, knowing the specifics of what your loved one wants in this situation enables you to carry out their wishes; this can provide peace of mind for both you and your care partner.

We recommend having a conversation, or a series of conversations, to discuss logistical issues, such as:

- **Financial Information**: What are their financial and billing account passwords? Who is in charge of their estate? Is there a life insurance policy? Do they have a will in place that's been updated to reflect their current wishes?
- **Medical Decisions:** Who is making decisions about your loved one's healthcare if they are no longer able to do so themself? Has a healthcare proxy (the person designated to make medical decisions) been chosen? Has a healthcare proxy form, which names the healthcare proxy and can include preferences and instructions regarding medical decisions, if desired, been signed by all required parties and submitted to the hospital where your loved one receives care?
- **Goals of Care for End of Life**: This can include considerations around hospice care, and if there's a preference for receiving it at home vs. at a facility; treatment preferences; pain management; quality of life; and your loved one's wishes regarding the use of any heroic measures, or aggressive medical interventions used to keep someone alive when certain vital organs or processes stop functioning properly (for example, tube feeding when someone is unable to swallow or digest food and mechanical respirators or ventilators for those unable to breathe independently).
- **Post-Death Planning**: Planning your loved one's funeral with them is understandably morbid, but many caregivers find it well worth it to broach this topic, despite how difficult and upsetting it can be. Talking about these details helps ensure that whatever is done to honor your care partner after they die reflects what they would have wanted. One of our Caregiver Mentor Angels spent time with her dying loved one crafting their obituary together and found that the process brought them closer. Perhaps your loved one wants a celebration of life instead of a funeral, or to be cremated with their ashes spread in certain locations instead of being buried in a cemetery. Whatever their preferences, find out what they are so you can try to make them happen.

Other factors can also have an impact. For LGBTQIA+ folks, for example, having your care partner's financial and medical wishes in writing can be even more essential. Some LGBTQIA+ caregivers have experienced their care partner's estranged relatives swooping in at the last minute, making decisions that aren't in line with their loved one's wishes, and locking them out of the decision-making process altogether. Putting your care partner's wishes in writing, in legally binding documents, can help protect against these types of situations.

Try to have these conversations sooner rather than later. One of our Caregiver Mentor Angels notes that addressing these important decisions early on can result in less stress and worry as your loved one nears the end of their

life. Additionally, by not having unresolved issues looming over you, you may be able to enjoy your remaining time together more.

Make plans for their legacy, too. There are so many logistics involved in end-of-life and post-death planning, it's easy to be overtaken by all the decisions that need to be made, often in quick succession. While this is important, it's not the only thing that matters: Many caregivers find it meaningful to also set aside time to talk to their loved one about their wishes for their legacy.

Some people get tripped up thinking that this has to be a "capital L legacy" – like making a huge financial donation to a charity, for example. But this couldn't be further from the truth. You don't have to have millions in the bank – or even spend a penny – for your loved one's memory and legacy to live on long after they're gone.

One of our Caregiver Mentor Angels asked her loved one who was nearing the end of her life where she wanted the wigs she used when she'd lost her hair from chemo to be donated. If your care partner loves animals, maybe there's a local animal shelter you'd like to request donations to in their name in lieu of flowers when you make funeral arrangements. Or perhaps your loved one would like their clothing or furniture to be donated to a specific organization that's meaningful to them.

Here are a few other suggestions for helping you honor your loved one's legacy:

- Compile their favorite recipes to make into a cookbook for your family to use
- Record conversations with them via audio or video to preserve their most treasured stories and memories
- Preserve their handwriting through written memories or notes
- Help them write letters to their children or other precious family members to read at various milestones (e.g., certain birthdays or school graduations)

What you choose to do will be different from person to person and there's really only one criteria: Find something that's meaningful to your loved one.

ADDITIONAL RESOURCES FOR END OF LIFE

In addition to **hospice care**, which is a medical service that focuses on providing comfort and pain and symptom management for people with terminal illnesses in the final days, weeks, or months of their lives, another option to consider is hiring a **death doula**, also referred to as an end-of-life doula.

Unlike hospice care, death doulas do NOT provide medical advice or care. Instead, they offer emotional; spiritual; and practical, logistical support to individuals nearing the end of life and their caregivers and family members. Through care and compassion, death doulas facilitate honoring and respecting the dying process.

Some services death doulas might provide include:

- Preserving memories
- Creating legacy projects and meaningful end-of-life rituals
- Clarifying wishes for medical care, funeral arrangements, and other end-of-life plans
- Offering respite care for caregivers to support them in being able to take breaks

As with any provider, do your due diligence before hiring someone. You can learn more about death doulas through the National End-of-Life Doula Alliance (NEDA) on their website here.

In addition, we've created a few more resources to support you and your care partner at end of life. Click the links below to download them.

- End-of-Life Conversation Starter Prompts
- Legacy Resources and Ideas Guide

NOTE FROM A MENTOR ANGEL

What you are going through is a sacred, poignant, and heartbreaking experience. This isn't a time to be hard on yourself; this is a time for great compassion and making memories.

Gently ease into end-of-life conversations about final wishes and financial concerns. Utilize the support from your hospice and your medical team. Trust them to handle the operations while you focus on more pressing issues. It's okay to just "be," and honor [your and your loved one's] choices, whether it's a place, a meal, or even a conversation.

Remember to eat and hydrate yourself, and take breaks to sustain your mental and physical health.

Finally, remember you cannot control the outcome. Release yourself from that expectation, and give [your loved one] your presence as they transition. You are a champion for fulfilling this tough obligation, so give yourself grace.

– Kandis
Caregiver Mentor Angel & Caregiver to Mother Diagnosed With Ovarian Cancer

Mentor Angel notes have been edited for length and clarity.

6. Loss and Grief

What to Expect

No one can prepare you for the grief that comes with the death of a loved one. One thing that can be disorienting for many caregivers is the mix of emotions that can arise in the wake of this loss.

Instead of just one dominant emotion, such as sadness, caregivers often also experience a sense of relief after their loved one dies. This can be confusing and prompt self-judgement and shame, causing people to wonder how they can feel relieved if they really loved them.

Experts stress that caregiving is one of the most difficult responsibilities, mentally, emotionally, and physically, that anyone can ever experience. So it's inevitable – and completely normal – to feel some sense of relief when actively caregiving for a loved one comes to an end.

It's important to know that this does *not* in any way take away from the love you feel for them and the sadness that they're no longer here. Relief, sadness, loss, and love can, and often do, coexist: You can miss them every day of your life, and still be relieved that you're not constantly worried about them and their well-being or that they're no longer suffering.

To help address some of the challenges



*specific to the loss of a loved one, we created our **Grief Toolkit**. It's listed in our Recommended Resources section in the back of this guide and you can download it here.*

What Can Help

Switch up your support to meet your current needs. Your needs as a caregiver constantly change, so it's important to continually assess how you're feeling and how to get the support you need. The death of your loved one is another key point to check back in with yourself, evaluate your support systems, and make adjustments as needed. This is also a time when you may need *additional* help and support.

For example, if you've been attending a caregiver support group, you might want to consider switching to a group focused on grief and the loss of a loved one. It can be helpful to attend a support group tailored to your specific phase, challenges, and needs – and emotionally triggering to go to ones that are out of sync with your current experiences.

Additionally, many people aren't aware that *Medicare-certified hospice providers are required to provide bereavement services,* such as grief counseling, to caregivers for up to 13 months after their loved one has died. This is a worthwhile – and free – option to look into.

Know that there's no timeline. The five stages of grief. One week of bereavement leave. Friends checking in with you for a month and then assuming everything is "back to normal." People only reaching out to see how you're doing on milestone days like your and your loved one's anniversary or their birthday.

These parameters give us the false idea that grief follows a certain timeline, and that it has a distinct beginning, middle, and end. In reality, grief is messy and complicated, and lasts longer than society gives us permission to feel.

Despite having the best of intentions, people who haven't experienced the death of a loved one likely won't fully understand what you're going through. Connecting with other caregivers who've experienced this loss can be helpful, through grief groups and peer mentorship like an Imerman Angels **Mentor Angel**. Professional support from a therapist or counselor, especially one with expertise in grief, can also be beneficial.

See page 16 for tips on finding a therapist and note that you can select "grief" as a search term to filter mental health professionals on PsychologyToday.com's therapist database.

Reflection Prompt:

What stage or stages of caregiving are you in right now? Which one or two suggestions from this chapter could you try out this week?

NOTES

Chapter 4: Caregiver Burden: Navigating the Difficulties

As we mentioned in the last chapter, caregiving can be one of the hardest experiences in existence and it comes with many difficulties. We've highlighted some of the most significant ones so you can be on the lookout for them; seek support if you notice any of these or other risks crop up.

Remember, you don't have to go through this alone. Asking for help isn't a sign of weakness. Reaching out for support is an act of strength – and you deserve support, too.

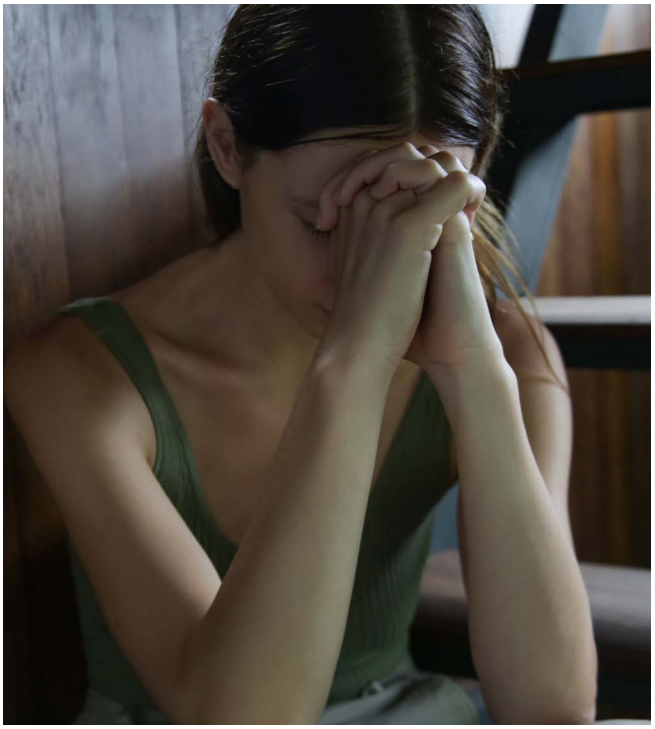
COMMON RISKS ASSOCIATED WITH CAREGIVING

Isolation

One in four caregivers report feeling isolated and alone. This can happen for a number of reasons. First of all, caregiving tasks keep you *busy*. Amid your caregiving responsibilities and daily household tasks, socializing and connecting with others can fall to the bottom of your list.

Then there's the emotional aspect. Early on after becoming a caregiver, many people start to feel a disconnect from others – even friends, family members, and coworkers they've previously been close to. Caregiving is such a distinct experience and unless someone has personally experienced it, they usually won't be able to fully understand what you're going through. On top of that, well-meaning advice from people who haven't been caregivers often misses the mark and can make you feel worse.

This feeling of disconnection and not being understood, combined with managing all the logistics caregiving entails, can lead to isolation and further withdrawal from social connection.



Caregiver Burnout and Compassion Fatigue

These two risks can sometimes be confused but they are actually two different, distinct issues.

Caregiver burnout is emotional, physical, and mental exhaustion that develops gradually, caused by the prolonged stress of the demands of caregiving. Its effects can be cumulative, worsening over time. Common signs can include feelings of frustration and irritability, anxiety, depression, and/or hopelessness. Sometimes physical symptoms, such as fatigue and sleep difficulties, headaches, muscle pain, and digestive disturbances can also be present.

Compassion fatigue is a collection of stress-related symptoms that caregivers may experience as a result of being exposed to the trauma and suffering of others (in this case, the person they are caring for), sometimes repeatedly or continually over time. Common

signs can include emotional numbness and loss of empathy or concern for yourself and others, mood swings, difficulty focusing, and loss of motivation or sense of purpose. Similar to caregiver burnout, physical symptoms, including headaches and digestive issues, can also be involved.

Key Differences

While there is some overlap between caregiver burnout and compassion fatigue, there are also a few important differences.

- Caregiver burnout tends to occur slowly over time; compassion fatigue can build over time but can also come on suddenly as the result of a traumatic event.
- With caregiver burnout you're able to maintain empathy; in compassion fatigue there's a loss of the ability to empathize.
- Recovery from burnout can take significant time; compassion fatigue recovery may be quicker but often requires help from a mental health professional. However, if you are experiencing signs of either caregiver burnout or compassion fatigue – or both – it's crucial to address it and get any necessary assistance.

Other Mental Health Risks

Depression, **anxiety**, and **PTSD** (post-traumatic stress disorder) are some of the most common mental health conditions that caregivers are at risk for. Research shows that approximately 40–70% of caregivers experience clinically significant symptoms of depression, with about a third of caregivers reporting anxiety.

There's a pervasive belief that PTSD only happens to certain individuals – soldiers who've been in combat or someone who's been the victim of a violent crime, for instance. In reality, PTSD is a lot more complex and far-reaching.

In the context of caregiving, PTSD can result from a single incident, chronic stress and trauma that builds over time, and/or secondary traumatic stress that comes from witnessing someone else's trauma – in this case, that of your care partner – among other triggers.

Below, we've included lists of some common symptoms for these three conditions. Note that these lists are not exhaustive; other symptoms exist and you may experience depression, anxiety, or PTSD differently.

Depression

- Feelings of sadness, emptiness, or hopelessness
- Uncontrollable tearfulness or crying
- Angry outbursts, irritability, and/or frustration that's easily triggered, even by seemingly insignificant things
- Loss of interest in hobbies or activities you used to enjoy
- Inability to sleep, or sleeping too much
- Difficulty thinking, concentrating, making decisions, and remembering things
- Tiredness and lack of energy to the point that even small tasks feel unmanageable

Anxiety

- Nervousness or restlessness
- Sense of impending doom or danger
- Increased heart rate
- Rapid, shallow breathing
- Trouble concentrating
- Difficulty controlling worry
- Trembling or shaking
- Upset stomach or other digestive issues
- Difficulty sleeping

PTSD

- Difficulty sleeping
- Digestive issues
- Headaches
- Persistent fatigue

- Racing thoughts
- Numbness or apathy
- Irritability and snapping at others
- Withdrawing from friends or activities
- Using alcohol or other substances to cope

There's a lot of overlap between these three conditions and it can be difficult to know which one(s) you're experiencing. We recommend seeking professional help if you're experiencing any of these symptoms and beginning to notice your mental health slipping.

We are not mental health professionals; to learn more about these and other mental health conditions, visit trusted medical websites such Mayo Clinic, National Alliance of Mental Illness (NAMI), or Mental Health America, or talk to your healthcare provider.

WHEN TO SEEK HELP IMMEDIATELY

In some cases, caregiving can be the perfect storm for a mental health crisis: never-ending tasks and responsibilities; an overloaded schedule; worrying about a loved one's health and well-being; not having the time or energy to attend to your own mental and physical health; financial strains and worries; having to keep everything together and not having enough, or any, support.

If you experience suicidal ideation, seek professional help immediately. The 988 Suicide & Crisis Lifeline is free, confidential, and always available 24 hours a day, 7 days a week, 365 days a year. Call or text 988 or visit their website https://988lifeline.org/ for more information.

Physical Health Risks

Caregivers can be under a tremendous amount of chronic stress, while not having the time or mental bandwidth to keep up with their own medical appointments. This can be compounded by the physical demands of caregiving – for example, assisting your care partner with their activities of daily living, such as lifting them in and out of bed or helping them go to the bathroom.

Research shows that caregivers tend to have worse physical health, and higher mortality (or death rate), than non-caregivers. This includes higher rates of cardiovascular disease, heart attacks, fatigue and sleep difficulties, and poor immune function, which in turn increases susceptibility to colds, flus, and other viral infections.

As our caregiving expert advisor Allison J. Applebaum, PhD puts it, due to prolonged, chronic stress and limited capacity to care for their own health and well-being, caregivers often become "the next patients" and may face serious illnesses themselves.

We're not saying this to scare you, only to stress that the demands of caregiving can be incredibly taxing and it's crucial to find a way to take care of your own health. A lot easier said than done, we know. So we've created a worksheet on page 45 to help sort out what medical checkups and screenings you're due for and start scheduling them.

COPING WITH COMPLICATED EMOTIONS

Anger, Resentment, and Shame

Caregivers often grapple with complicated emotions, and **anger**, **resentment**, and **shame** came up time and time again in our conversations with experts and caregivers alike. What this tells us is that these feelings are *very* common, and most if not all caregivers experience them at some point.

The first step is letting go of any self-judgement that may arise and realizing that these feelings are a normal part of being a caregiver – and actually, of being a human being in general.

Taking it a step further, experts say that these

emotions carry important information. Here's what they may be trying to tell you.

Anger: Learning this one piece of wisdom was so eye-opening for us and completely shifted our perspective: *Underneath anger is sadness.*

When you feel angry, experts recommend asking yourself, "What am I grieving?" Remember, grief doesn't only have to do with death; it can also occur over the loss of the person your care partner was before they were diagnosed with cancer, the loss of the future with them that you envisioned, or even the loss of your ability to plan more than a few weeks in advance.

Exploring the sadness underneath your anger can help you get in touch with its root cause and start to lessen the intensity of this uncomfortable emotion.

Resentment: This is another emotion that comes bearing clues about what you need in that moment. It's common for caregivers to feel resentful of your care partner – and does not in any way negate the love you feel for them. You may resent the sacrifices you need to make to care for them, the personal and professional opportunities you've lost, or the way your identity has shifted.

You may also resent having to bear the caregiver burden alone, without meaningful – or any – help and support from family members and friends.

Resentment carries another important message: It's time to do some problem-solving around expanding your support network. Although this can be time-consuming and difficult, you need to find people you can delegate tasks and responsibilities to so you don't have to continue doing it all yourself.

See "Chapter 6: How to Get the Support You Need" on page 34 and our "Building Your Caregiving Support System Worksheet" on page 47 for tips on building and expanding your support network.

Shame: The third in our trifecta of complicated emotions, shame is another emotion that caregivers are *very* familiar with. Like anger and resentment, shame often tells us something about what we need.

Caregivers can experience shame for feeling angry and resentful, or anything but purely loving toward their care partner. You may have thoughts like, "I wish I didn't have to do this anymore" or "I just want to sleep in for one day instead of waking up at the crack of dawn to check on them," – quickly followed by the thought, "I'm a horrible person!" and a wave of shame.

When these thoughts, and the shame that comes with them, arise, experts suggest questioning them. Ask yourself, "Am I really a terrible person? Or am I just tired, sad, and depleted?"

What you'll probably discover: Similar to resentment, shame also tells us that we may be stretched too thin and need more support.

DEALING WITH DIFFICULT SITUATIONS... AND DIFFICULT PEOPLE

Conventional caregiving advice usually assumes that your care partner is appreciative of your efforts and constantly expressing their gratitude – but we know that this isn't always the case.

Caregiving is hard enough when your loved one is kind and loving and appreciates everything you do for them and all the sacrifices you make. Add in a difficult care partner who is hard to get along with and it can become nearly impossible, taking even more of a toll on your mental and physical health.

These difficulties can happen on a spectrum from more to less manageable to downright intolerable. Here are some situations you may encounter – and a few helpful strategies for dealing with them.

1. Not feeling appreciated by your care partner.

Your care partner is navigating cancer treatment and side effects, while possibly also

facing their own mortality and the fear and anxiety that brings. No matter how much they love and appreciate you, because of what they're going through, they might not always express their gratitude.

While it doesn't feel good when your efforts seem to go unnoticed, it can be very difficult to bring up this topic with someone who's going through their own serious health struggle; it's easy for this conversation to go awry and for both you and your care partner to wind up more upset and unhappy in the end.

Before discussing feeling unappreciated with your care partner, you may want to talk about your feelings with a therapist or share your concerns in your support group or with a peer mentor first. Having a sounding board like this can help you get ideas on how to best and most sensitively approach the conversation, which is going to be different in every relationship.

Talking it out, especially with a therapist or other calm, neutral third party who isn't going to fan the flames of your anger and resentment, can also help diffuse the intensity of your emotions and give you perspective. So when you do have a conversation with your loved one, you'll be able to do so in a calmer way that in turn, they'll be more receptive to.

2. Being mistreated by your care partner.

This is where it starts to go from something you can overlook to something that can make your day-to-day life unmanageable. What's more, sometimes this behavior is a complete about-face from how your care partner usually acted. If they were always kind and suddenly they easily lose their temper with you, it's important to investigate the underlying cause.

Sometimes the cancer itself and/or certain treatments and medications can trigger changes in behavior. So it can be helpful to talk to your loved one's doctors and try to find out what's causing these bursts of anger or other personality changes.

If it's being triggered by the disease or treatment, when your loved one lashes out at you it can be helpful to tell yourself, "This is the cancer speaking," or "This is the medication talking" – "This is not my partner/father/mother, etc." This can help create some distance and take their behavior less personally.

3. Having to be a caregiver for an estranged relative.

Sometimes, people find themselves in the incredibly difficult situation of having to be the caregiver for someone they'd previously cut ties with, such as a parent, sibling, or former significant other. Having little to no contact with a family member or previous partner is usually a last resort, after other, less dramatic options like setting boundaries have been unsuccessful.

But if your estranged family member gets diagnosed with cancer and there's no one else who can take care of them, you might wind up stepping up as their caregiver.

First of all, know that this is a tremendously difficult situation and validate yourself for all you're doing. Next, it can be helpful to connect to your "why" – the reason that's driving you to take care of them. Perhaps deep down, part of you feels that it's the right thing to do and aligns with your values.

Even though the relationship is complicated, you may still be able to experience meaningful moments of connection. In some cases, you might even have the opportunity to repair your relationship. But going into it expecting that outcome could lead to disappointment. Instead, focus on your own inner experience; being able to look back and know that you stepped in to take care of them and did your best can provide a sense of peace in the bereavement process.

4. Being on the receiving end of abusive behavior.

There's a point when a line gets crossed and the behavior of the person you're caring for goes from being unpleasant and hard to

tolerate to abusive and unacceptable. If, as their caregiver, you're being continually exposed to verbal, emotional, physical, or any other type of abuse, it's important to recognize that what you're experiencing matters, too.

Being someone's caregiver does not mean you have to accept being a target of the person's anger, mistreatment, or frustration. At the same time, we recognize that stepping back or changing a caregiving arrangement is not always simple – or even possible. You may be the only person available; you may not have the financial resources to hire additional help; or you may experience feelings of guilt, responsibility, or obligation that make it difficult to consider stepping away.

If you find yourself in this situation, you don't have to figure it out alone. Start by talking with a hospital social worker or patient navigator. They may be able to help you explore available resources, community programs, or other ways to make the situation safer and more manageable for yourself. One option to consider is **respite care**, which is the umbrella term for programs and services that enable caregivers to take a break for anywhere from a few hours to several weeks through in-home care and onsite options at a healthcare facility.

If you have the financial means and access to do so, hiring home health aides or other direct care workers may provide some relief and create a little distance between you and the day-to-day demands of caregiving. But if hiring help isn't an option, that doesn't mean you simply have to endure the abuse. There may be other resources or changes that can help create boundaries and protect your well-being.

And if you are in a situation that is unsafe for your mental and/or physical well-being, you can contact the National Domestic Violence Hotline to speak with an advocate. Their services are free, confidential, and available 24 hours a day, 7 days a week. Call them at 1-800-799-SAFE (7233) or visit their website at thehotline.org.

Reflection Prompt:

What is currently the hardest part of being a caregiver for you? What are one or two actions you can take this week to try to ease this particular burden?

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Chapter 5: Caregiver Joy: Examining the Benefits



Caregiving can be immensely difficult and bring with it a number of burdens, but there's also joy to be found in the act of caring for another person. To gain a balanced perspective – and not get bogged down by the negatives – it can be helpful to take a look at some of the benefits.

First, it's important to acknowledge that there can be significant cultural differences in how people experience caregiving. For example, Black and Hispanic/Latinx cultures tend to place a higher value on responsibility for extended family and taking care of others in your community, versus the focus on individualism, self-reliance, and the smaller nuclear family unit that's more prevalent in Caucasian groups in the United States.

In BIPOC (Black, Indigenous, and People of Color) communities, people often don't think of caregiving as a burden, in part because there's a norm of caring for sick family members and stepping into the role of being a caregiver for an ill or aging parent. In fact, it can be a rite of passage. When adult children take care of their parents, there's an additional benefit: It models this value and responsibility for *their* children.

But regardless of your cultural, racial, or ethnic background, there are several universal benefits that come from caregiving and it's important not to overlook them. Below, we've detailed some common benefits that caregivers experience.

BENEFITS OF CAREGIVING

Realignment of Values

It's easy to get caught up in day-to-day minutiae and lose sight of the bigger picture. We've all been guilty of thinking that which rug we order for the living room is the most important decision we'll ever make, or that the outcome of our life hinges on a work deadline.

Caregiving gives you instant perspective on what truly matters (spoiler alert: it's not the rug or the work deadline!), and provides the opportunity to zoom out of the day-to-day grind and take a deeper look at what's really important to you.

And if you've gotten off track in your life and found yourself in a place where you're not that happy – whether in your career, relationships, or any other area – the insights you glean along your caregiving journey can help nudge you onto a path that feels more true to you and who you want to be. In this way, caregiving, similar to any serious diagnosis, can serve as a wake-up call.

Increased Sense of Purpose and Meaning

Caring for another person in this way can be incredibly fulfilling in and of itself. After all, as a caregiver, you're doing arguably the most important work there is. Many caregivers find meaning in the tasks and responsibilities that come with the role and enjoy having the opportunity to take care of a loved one.

Caregiving can also connect you to a larger sense of purpose that perhaps you'd lost touch with. In some cases, this can even prompt you to pursue a different career, take up new hobbies, or volunteer. For instance, after their experiences seeing the impact of healthcare workers up close, some caregivers have gone back to school to become a nurse or other healthcare professional. And many of our Caregiver Mentor Angels signed up for this role to use their personal experiences as caregivers to help others in similar situations.

Just remember that you don't have to make a complete about-face in your career or take on a ton of volunteer commitments to find purpose and meaning in caregiving – it's available every day in ordinary tasks and being present with the person you're caring for.

Strength and Resilience

Caregiving has a way of teaching you that you're stronger than you thought. Maybe you've been shy all your life and have had a hard time speaking up for yourself. But then, caregiving helps you find your voice as you advocate for your loved one with healthcare providers, billing departments, and insurance companies.

Or perhaps you used to get easily overwhelmed or upset by insignificant annoyances, and now you find yourself able to face the most important decisions about your loved one's care with confidence.

When you become a caregiver, you don't necessarily have a choice about the challenges you'll have to handle. But many people find that they rise to the occasion, discovering that they're stronger and more resilient than they ever expected.

Download our **Side Effects & Self-Advocacy Resource Guide** here for tips on how to advocate for yourself and your care partner within the healthcare system.

Resourcefulness: Becoming the "Ultimate Problem-Solver"

Caregiving also gives you concrete skills, like multi-tasking and problem-solving. Resources aren't easily available and solutions are rarely placed in front of you. So you *have* to be resourceful to get your and your care partner's needs met. This gives you determination, perseverance, and the self-assurance that you won't stop until you get an answer.

From researching treatment options and doctors to scheduling appointments, coordinating care, tracking down support groups and clinical trials, and managing meal drop-offs, caregivers are masters of organization; no matter what is required, you find a way to make it happen. So much so that one of our Caregiver Mentor Angels calls caregivers "the ultimate problem-solvers."



Love, Connection, and Time Together (Plus Laughter!)

The truth is, were you not a caregiver for your loved one, you might not have this time to spend together. Even though it's not under ideal circumstances, many caregivers value this time with their care partners and find

that it brings them closer. In circumstances where care partners are living with life-limiting cancers, the memories you make together can also help in the grieving process after their death.

There's a misconception that once someone is diagnosed with cancer, the rest of their (and their caregiver's) life is going to be dark and miserable. In reality, cancer isn't just one thing – it's a mix of all kinds of experiences and emotions. And people are more than their cancer diagnosis or caregiver role.

There can be pain, difficulty, and sadness one day, and the next day (or even minute!), there's joy and laughter. In fact, people who haven't experienced a cancer diagnosis personally or in a loved one would probably be surprised at how much humor – albeit often *dark* humor – and laughter can be found amid the difficulties. Even on the hardest days, a moment of joy might pop up and surprise you.

This isn't about toxic positivity, finding the silver lining, or looking on the bright side. It's about letting go of preconceived notions of caregiving as being *only* burdensome, seeing all sides clearly, and gaining a more balanced perspective.

Despite the difficulties, our Caregiver Mentor Angels have often described it as a privilege and honor to be able to care for their loved ones in this way.

Acknowledging the upsides of caregiving can help you withstand the harder times. And consciously cultivating and claiming these benefits can aid you in stepping into your sense of power and agency.

Reflection Prompt:
Try to identify one to two benefits you've experienced as a result of being a caregiver. How does it feel to think about these positive aspects?

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Chapter 6: How to Get the Support You Need

If you take away only one thing from this guidebook, let it be this: As a caregiver, you deserve to receive the support you need. No one person can do everything by themself – and you shouldn't have to.

HERE ARE A FEW THINGS YOU SHOULD KNOW:

- Struggling with overwhelm as a caregiver is *not* a personal failure – it's part of a larger, systemic problem that places too much burden on unpaid and untrained individual family caregivers and doesn't provide enough assistance, resources, and support.
- Caregiver responsibilities often fall disproportionately on *one* person. For example, instead of all siblings chipping in to support a parent with cancer, it's very common for one sibling to take on everything and for the rest to go on with their lives, business as usual, without even making the smallest contribution. You don't have to spend long in caregiver support groups, caregiver social media comments sections, or other online spaces to see that this is a pattern, and a widespread problem. If this is your experience, know that you are far from alone!
- Although you and your loved one are both navigating their cancer diagnosis together, you still have your own individual experiences, emotions, fears, and needs. It can be beneficial for both you and your care partner to each have your own support system; this can help provide connection and understanding and ease feelings of loneliness, isolation, and overwhelm for both of you.



You May Need Additional Support If...

Before we get into the different ways to get support, we also want to mention that certain situations make building a support system even more essential.

First of all, some people start off with smaller support networks from the get-go. This can be the case for folks in marginalized communities, individuals who are estranged from relatives and don't have extended family to rely on, and single people caring for a parent, sibling, or child, for instance. When a strong support system isn't present to begin with, it becomes even more important to fill in these gaps and make up the difference.

Another scenario that comes up a lot is when your care partner is a private person and doesn't want anyone to know about their diagnosis.

As their caregiver, this puts you in a bind: Of course you want to respect your loved one's

wishes, but their desire for privacy seriously limits your support circle. For caregivers who can't talk about their loved one's diagnosis (and their own experience and struggles of being a caregiver) with mutual friends or family members, support from a neutral third party outside of your and your care partner's circle can become a lifeline.

Caregivers in this situation have found that working with a therapist can be helpful, and having a peer mentor can also be a beneficial outlet and support option. Usually, an Imerman Angels Caregiver Mentor Angel won't know your care partner, and they may not even live in the same town or part of the country. A Mentor Angel can be the confidant you need when you can't talk to friends and family about what you're going through.

When seeking this type of support, caregivers often talk it over with their care partner out of respect for them. If you're in this situation, you can kick off the conversation with your loved one by saying something like, "I need support in what I'm going through but to honor your privacy, I'm not going to talk to anyone we know about it. I've found a [therapist or Mentor Angel] who doesn't know you or anyone we know, and who will keep our conversations confidential. I hope you understand that I need this outlet to be able to take care of myself and ensure that I can continue to support you."

Why Caregiver Support Is Necessary

There are a *lot* of resources available for people who've been diagnosed with cancer, and after your loved one's diagnosis, you're often bombarded with this information from every direction. On the flip side, there's a clear lack of resources designed for caregivers. While this is starting to change, with more programs and services devoted to caregivers, there's still a lot of catching up to do.

Caregivers' needs often slip into the background, and some caregivers report feeling like they're invisible and their needs don't matter. As a caregiver, you're expected to show up day in and day out to attend to your loved one, and days, weeks, and months can easily go by without anyone asking how *you're* doing.

This is why getting support is so essential – it helps you connect with others, including mental health professionals and other caregivers; share your difficulties; and find solutions. Isolation is a common occurrence for so many caregivers, and as time goes on it can feel like you're falling into a bottomless pit of loneliness. Social, emotional, and spiritual support can help you feel seen, combat isolation, and ease loneliness.

BUILDING YOUR SUPPORT SYSTEM

As we mentioned, people aren't exactly lining up to give you caregiver resources, and it can take a lot of time and effort to research available options. To make it easier, we've created the following guide of places to look for resources and support. We've also included a worksheet on "Building Your Caregiving Support System" on page 47, and a curated list of recommended resources in the back of this guidebook.

Cost can be a real consideration, and for many people, a barrier. Most of the resources we've included are free, with a few exceptions like private practice therapists, for instance. If you're struggling financially, there are still many free or low-cost support options and resources available. We encourage you to talk to a hospital social worker or patient navigator, or call a free cancer resource navigation helpline like Cancer Support Community's at 888-793-9355 or CancerCare's at 800-813-HOPE to help you find accessible resources that meet your needs.

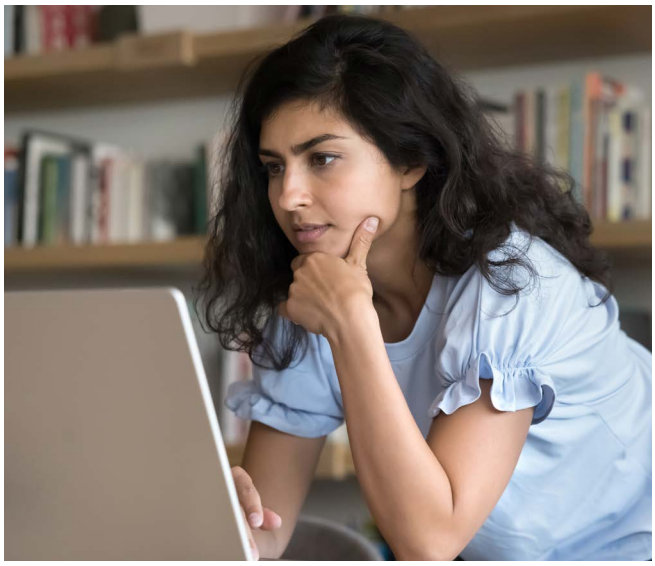
Start Here: What's Available in Your Community?

The first step we always recommend is talking to a hospital social worker about what local options are available. This can include free resources and support services provided at

the hospital for patients *and* caregivers, such as meditation workshops, counseling, in-person support groups, nutritional education, and more. Also ask about offerings in your community, particularly if there are any cancer nonprofits in your area, which often provide programs and services for caregivers alongside those for people diagnosed with cancer.

Broaden Your Search

Next, expand your search to national cancer and caregiver nonprofits. Many of these organizations offer resources and programs virtually, regardless of where you live. Another option that people often aren't aware of is that some hospitals, particularly large cancer centers, offer select programs that are open to everyone, even if your loved one isn't a patient there.



Go Online

Since the pandemic, virtual support groups and programs have become a lot more common. In fact, most large cancer support organizations offer at least some online support group options.

Everyone has a different comfort level when it comes to seeking support. If support groups aren't your thing, there are plenty of other possibilities, such as private Facebook groups to join, social media accounts to follow, and other online forums dedicated to caregivers to drop in on. There, you can participate according to your comfort level, whether that means just reading posts and consuming content, or becoming an active participant and posting.

A caveat: The internet can be the Wild, Wild West filled with trolls and dangerous misinformation. When you find an online group you want to try, we recommend sussing things out for a bit at first. Before jumping in and disclosing your feelings and difficulties, take some time to observe the interactions and group norms to make sure it's a safe space.

Seek Professional Help

There can be a stigma surrounding mental health, but you don't have to be going through a mental health crisis to benefit from therapy. In fact, taking care of your mental health *before* there's a crisis can help manage the emotional difficulties of caregiving – and life in general!

If you do get to a point where your mental health is suffering and you're experiencing any of the struggles we talked about in Chapter 4 "Caregiver Burden: Navigating the Difficulties," like caregiver burnout, compassion fatigue, anxiety, depression, and/or PTSD, it's crucial to seek professional help from a therapist, counselor, or other mental health professional. Psychiatry might also be an option; while again, there can be stigma associated with taking medication for your mental health, many people benefit from it and find it makes a significant positive difference, when clinically appropriate.

Seeing a therapist can require an investment of time and money, which can be a barrier. If you're in this situation, we encourage looking into free and low-cost options. Ask a hospital social worker what possibilities exist or call around to cancer nonprofits like CancerCare and Cancer Support Community to see if they have any recommendations.

Some mental health professionals offer a sliding scale, and many now offer virtual sessions online, making therapy a lot more accessible for people who live in remote areas

or are crunched for time or money.

Most therapists will allow you to book an initial consultation or at least a quick introductory phone call for free; take advantage of this option to get a sense of if you click with them before making a financial commitment.

In general, a mental health professional is a good person to include in your support system if possible.

For more tips on finding a therapist, see the "Mental Health Support for Caregivers: Where to Start" section on page 16.

Turn to Your Faith

If you are involved in a local faith-based community or spiritual center, don't overlook it as a potential source of support. This could come in the form of formal, structured support, like an imam or rabbi who offers one-on-one counseling, or a church support group for caregivers. For example, New York Zen Center for Contemplative Care hosts a bimonthly caregiver support group online.

As is true in many cases, you don't know what's available until you start asking. So it's worthwhile inquiring if your place of worship provides any services or programs that meet your needs.

The other way faith-based organizations can play a role is through informal support from other members. You might find people within your faith-based community who can help cook and drop off meals, accompany your care partner to chemotherapy appointments, pick up groceries, do home cleaning and laundry, or assist with other tasks you could use help with.

Get a Mentor Angel

A peer mentor is a great addition to your support network. It can be difficult for some people to find a support group they click with, and not everyone feels comfortable sharing personal details and being vulnerable in front of a group.

Having a peer mentor, like an Imerman Angels **Mentor Angel**, can be a lifeline. Peer mentorship doesn't have to be a replacement for support groups. Many people like having *both* and turn to them for different purposes. Sometimes you may have a question you want to run by a group to collect a variety of responses, and other times one-on-one encouragement is what you need.

At Imerman Angels, Mentees are matched with a Mentor Angel, who is a trained volunteer with similar circumstances. There's also a lot of flexibility on how people interact with their Mentor Angels, and this support is designed to meet the preferences and needs of Mentees.

For example, you can decide how you prefer to communicate with your Mentor Angel, whether that's via email, texting, phone calls, or video chats, and how often. Some Mentees just want to have one call, others like to communicate regularly with their Mentor over a period of several months, and some Mentees develop lifelong friendships with their Mentor Angels. It's up to you and what you prefer, and the relationship can evolve to meet your changing needs.

Visit imermanangels.org or call 1-866-IMERMAN (463-7626) to learn more and sign up – it's free!

Be Open to Support Coming from Unexpected Places

Oftentimes, people you thought you could rely on disappoint you when you need them most, and family members and close friends are unable to show up for you during your caregiving journey.

If this is true for you, here's a helpful tip: **Think outside the box**. Experts and caregivers alike have found that support can come from the most unexpected places.

In our experience, sometimes the people we were sure would be there for us let us down. (Don't take it personally, though – it usually says more about their own capacity and limitations than it does about you.) But other people we barely knew surprised us by rising to

the occasion.

Is there a neighbor who always smiles at you when you pass each other in the morning? Another regular at your favorite local coffee shop with whom you exchange pleasantries every day? An old college classmate who often offers words of support on your social media posts?

You don't necessarily even have to ask for help directly. If you and your care partner feel comfortable being open about their diagnosis, just sharing about what you're going through often prompts people to offer support in surprising ways.

To give you a few ideas of possibilities, here are some ways people we barely knew have shown up for us and our loved ones after a cancer diagnosis:

- Dropped off groceries, meals, and morning coffee
- Sent meal-delivery gift cards for services like Seamless and Grubhub
- Offered to come to chemo appointments
- Offered to help with home cleaning and laundry

This isn't a rare occurrence either – many caregivers experience this phenomenon. Make room in your support-system strategy for unexpected helpers.

Reflection Prompt:

Which type of support listed in this chapter is the most appealing to you? Is there one step you can take this week toward getting this support if you don't already have it?

(For example, research online support groups, schedule a free introductory consultation with a therapist, ask your religious leader if they do one-on-one meetings or counseling sessions with congregants, sign up for a Mentor Angel, etc.)

NOTES

Chapter 7: Realistic Self-Care Strategies for Caregivers

Ask any caregiver and they'll tell you: Self-care is a hot-button topic!

We've gone through some of the burdens of caregiving in Chapter 4, and we all already *know* how important it is to take care of ourselves. Finding the time, energy, money, and mental bandwidth is another story!

Here are some phrases many caregivers we talked to are sick of hearing because they're not actually helpful:

- *"You have to put on your own oxygen mask first."*
- *"You can't pour from an empty cup."*
- *"You just need to do some self-care!"*

Why the Concept of Self-Care Falls Short

First of all, it's important to recognize that if you are struggling to take care of yourself, this isn't a personal failing – it's a systemic problem. We often feel shamed by the cultural pressure to "do self-care," and as a result wind up thinking things like, "What's wrong with me? Why can't I get it together and take care of myself?"

This can even get framed as "self-neglect," which puts all the blame and burden on us – when in reality, we'd be able to take better care of ourselves if our society and its systems were set up better.

Next, conventional ideas of self-care have become so commodified and superficial:

Go to a spa! Take a bubble bath! Get a mani-pedi! Take a vacation!

None of these activities is truly going to address the root cause of caregiver burnout, and most of the self-care ideas people commonly suggest aren't even realistic or accessible from a time and money standpoint.



REDEFINING AND RECLAIMING SELF-CARE

To make self-care meaningful – and actually helpful – for caregivers, we need to redefine it to serve our purposes. For simplicity's sake, let's break it down into two main categories.

1. Physical Health

While some people are busy recommending spa services, they're overlooking one of the most important components of self-care: Taking care of your physical health. Scheduling doctor appointments is pretty mundane and not as glamorous as a spa vacation – but it's way more important when it comes to caring for yourself.

As caregiving expert Allison J. Applebaum, PhD says, "Caregivers are the next patients." Because of all the physical and mental health risks associated with caregiving, it becomes

extra important to stay current with your doctor appointments.

Finding the time for this is *not* easy. To help make it easier, we've put together a checklist of routine, preventive medical appointments and important screenings on page 45. Take some time this week if you can to start filling it out and scheduling your appointments.

2. Overall Well-Being

The rest of any potential self-care activities that aren't doctor appointments fall into this category.

CREATING A SELF-CARE STRATEGY THAT WORKS

To start taking back the idea of self-care in a way that doesn't make you want to hurl your phone across the room when the person you're talking to suggests "filling your cup," try our strategy for self-care that's meaningful and makes a difference.

1. Put a weekly planning session on your calendar.

We often hear the advice to "schedule in self-care like we would any other appointment," but it can be really hard to do this every day. In the spirit of keeping things simple, Applebaum suggests blocking out ONE one-hour timeslot (but 30 minutes is fine, too, if that's all you can manage!) on your calendar each week for self-care planning – AKA taking care of yourself. It's helpful if this is during regular business hours if possible, because that's the time when you can reach medical providers to schedule appointments.

Use this time to dedicate to your own self-care, whatever that means to you that week. Schedule the mammogram or prostate exam you've been putting off. Make a list of the things you need help with and another list identifying people who might be able to chip in. Brainstorm self-care ideas that are actually doable within your time, energy, and financial constraints. Sign-up for a caregiver support group or research therapists who have expertise working with caregivers and offer a sliding scale. Often, we can be too busy and run-down to even know what we need. Let this be a time you give yourself to think about what you need most and try to make it happen in a manageable way.

You can also use this time each week to fill out some of the checklists and worksheets we've included toward the back of this guidebook.

2. Think small.

Most of us aren't taking a spa vacation at a mountaintop resort or going on a cruise around the world anytime soon. Self-care has been distorted to mean something big (and usually expensive), and this isn't accessible for most of us. That's okay! These bloated, superficial ideas of self-care aren't any more beneficial than the smallest action you take in support of your own well-being.

When it comes to self-care, the most important thing is that you're actually able to do it. As you're thinking of ideas, challenge yourself to think *small* – the smaller, and easier to do, the better! We've provided some suggestions on the next page to get you started.

3. Maintain one pre-caregiving hobby or routine.

One of our Caregiver Mentor Angels recommends picking a hobby or routine you enjoyed before you became a caregiver and carving out time to continue doing it. For her, it's working out, but it could be anything that's important to you. While last-minute emergencies and schedule changes commonly arise when you're a caregiver, our Mentor Angel suggests protecting the time you block off for your chosen activity as much as possible.

4. Don't wait for permission.

Many caregivers think that they aren't allowed to take care of themselves until they cross off everything on their to-do list and every single thing they need to do for their care partner is handled. Spoiler alert: The day will likely never come when every task is complete and nothing remains on your to-list. Don't wait for

permission to take a little time for yourself. Our Caregiver Mentor Angels recommend giving yourself this permission today!

Self-Care Ideas for Caregivers — From Other Caregivers

Here are some self-care suggestions from caregivers and experts. Borrow anything you like and use this list as a jumping-off point for your own ideas, too.

- If the hospital your care partner is being treated at has an outdoor courtyard or light-filled atrium, sit there for a few minutes in between appointments.
- Add on a few minutes to your shower.
- Watch a favorite TV show.
- Take a walk around the block.
- Listen to a podcast episode while you're cleaning up, folding laundry, or washing dishes.
- Organize your cabinets or refrigerator if it makes you feel better.
- Meditate for five minutes. Set a timer or use a free app like Insight Timer, Medito, or Buddhify for short guided meditations if you'd like.
- Sit for 10 minutes at the end of the day with a soothing hot cup of your favorite tea.
- Go to a local library. Check out a book or just sit there – it's free!
- Don't do *anything* for five minutes.

Reminder: Self-care is about preserving energy, so just as important as adding in nurturing activities is saying "no" to people and places that drain you. Prioritize people and activities that support and nurture you – and decline everything else if you can.

Use our "Realistic Self-Care Planning for Caregivers Worksheet" on page 49 to brainstorm self-care ideas that feel manageable and appeal to you.

Reflection Prompt:

What are one or two self-care ideas that feel manageable to you? Try to do one this week if you can. Remember: Think *small!*

NOTES

Chapter 8: Bringing It All Together

"[Caregiving] was the most exquisitely beautiful *and* painful experience of my life."

– **Allison J. Applebaum, PhD** in her book ***Stand by Me: A Guide to Navigating Modern, Meaningful Caregiving***



We created this **Cancer Caregiver Companion** because we saw a gap in social and emotional support for caregivers. Identifying and addressing the most pressing caregiver psychosocial needs, and recognizing that caregivers are often short on time and energy, we've compiled everything we wish we'd known when we were starting out on our caregiving journey.

While we've centered this guide around psychosocial support, we also know that nothing occurs in a vacuum and all the various caregiver responsibilities and needs are interconnected. One way this manifests is that the accumulation of logistical tasks associated with caregiving can impact physical, emotional, and mental health and lead to overwhelm and burnout.

For this reason, our Recommended Resources list in the back of this guidebook includes a section on places to get logistical help on things like workplace and legal issues, organizing and managing meal drop-offs and other support tasks, and tracking your loved one's appointments and medications, for example.

Our Resources List is itemized by category to make it easier to find what you're looking for.

As we mentioned, we designed this guide for you to be able to read cover to cover, OR just flip to whatever section or page you need in the moment. We hope you'll keep it handy and return to it often, whenever you need comfort and encouragement.

Caregivers face unfathomable challenges and unique joys, and no one can understand the caregiving experience quite like someone who's been through it can.

At Imerman Angels we envision a world where cancer is not a solitary experience. Our mission is to provide comfort and understanding for all cancer fighters, survivors, previvors, and caregivers through a personalized, one-on-one connection with someone who has been there. Having a Mentor Angel can be an invaluable part of your support system as a caregiver.

Contact us at imermangels.org or 1-866-IMERMAN (463-7626) to learn more.

We can't wait to hear from you!

Reflection Prompt:

What is one takeaway you got from reading this guidebook? Is there anything you'd like to try implementing in your life?

NOTES

Worksheets & Checklists

My Medical Appointment Tracker

Caregivers' Guide to Managing Your Own Medical Appointments

To help get you started, we've included a few standard, routine preventative medical appointments and common screenings in this template, plus blank lines for adding any more that are necessary for you. Note that this is just a starting point and not an exhaustive list.

We've also included a section for Mental Health in case this is something you'd like to incorporate into your overall well-being.

There are general recommendations for how often each appointment should be scheduled but yours might be different, depending on your specific medical history and any pre-existing conditions. We recommend bringing this list to your next appointment with your primary care doctor and asking them to help you fill in which appointments you should be scheduling on a regular basis and when.

Year: _____ **Today's Date:** _____

Appointment Type	**Provider**	**Timeframe Due**	**Scheduled For** (Date)	**Insurance Referral Obtained, If Needed**
Ex: Primary Care Provider (PCP)	Dr. Smith	Annually, in January	1/25	
PHYSICAL HEALTH				
PCP				
Gynecologist				
Dentist				
Dermatologist/ Skin Check				
Eye Doctor				
All other specialists below as applicable (e.g., urologist, cardiologist, etc.)				

SCREENINGS				
Mammogram				
Pap Smear				
Prostate				
Colonoscopy				
VACCINES				
MENTAL HEALTH				
Therapist				
Other Mental Health Professionals				

Building Your Caregiving Support System

Step 1: Identifying My Caregiving Network

Make a list of all the tasks you need help with, divided into two categories: Caregiving Tasks (e.g., taking your care partner to chemotherapy appointments, setting up a GoFundMe) and Routine Household & Life Tasks (e.g., childcare, school pickup, dropping off prepared meals). Then start to brainstorm people who you could ask to help with specific tasks, who may have the right availability or skillset to pitch in in specific ways.

CAREGIVING TASKS

Tasks I Need Help With	**Who Could Help?** Consider availability and skills

ROUTINE HOUSEHOLD & LIFE TASKS

Tasks I Need Help With	**Who Could Help?** Consider availability and skills

Step 2: Finding Social & Emotional Connection

Do any of the social and emotional support options from Chapter 6 “How to Get the Support You Need” sound appealing to you? Is there anything you’d like to look into? Here’s a list to keep track of possibilities you’d like to try.

Type of Support (e.g., support groups, faith-based community, Mentor Angel)	**More Information/How to Sign Up** (include the hosting organization's name and/or website here)	**When Does It Meet?** (if applicable, or list it as "varies," for example)

Step 3: Supporting My Mental Health

Are you interested in building out your mental health team with a therapist and/or other mental health professionals? If so, here’s a place to keep track of referrals and recommendations as you work to find the right mental health professional(s) for you.

Mental Health Professional	**Website**	**Fee**	**Accepts My Insurance** (Yes/No)	**Recommended By**	**Notes**

Realistic Self-Care Planning for Caregivers

My Weekly Self-Care Planning Session Is Scheduled For: _____

MY ONGOING LIST OF SELF-CARE IDEAS

What self-care practices do you want to incorporate into your life? Jot down anything from Chapter 7 "Realistic Self-Care Strategies for Caregivers" that appeals to you or add your own ideas below.

-
-
-
-
-

SELF-CARE ALSO MEANS SAYING "NO"

What can you say "no" to?

-
-
-
-
-

MY SELF-CARE PLAN FOR THIS WEEK

List a few self-care ideas you'd like to try this week – you can pick from both "Self-Care Ideas" and "Things to Say 'No' To" categories. Remember: Think *small!*

-
-
-
-
-

Recommended Resources

MORE HELPFUL RESOURCES FROM IMERMAN ANGELS

Grief Toolkit	**Read**
End-of-Life Conversation Starter Prompts	**Read**
Legacy Resources and Ideas Guide	**Read**
Relationships After Cancer Resource Guide	**Read**

LOGISTICAL INFORMATION, TOOLS, & SUPPORT

Care Coordination

CaringBridge	**Learn More**
Lotsa Helping Hands	**Learn More**
Meal Train	**Learn More**

Financial, Work, & Legal

Cancer + Careers	**Learn More**
GoFundMe	**Learn More**
Health Access Innovation (helps appeal denied insurance claims for free)	**Learn More**
Triage Cancer's Cancer Caregiver Resources	**Read**
Triage Cancer's Practical Guide to Cancer Rights for Caregivers	**Read**

Medication Management

Medisafe App	**Download**

Other

Cancer Support Community's 10 Tips for Navigating Logistics as a Caregiver	**Read**
Cleaning for a Reason (free homecleanings for households where someone is undergoing cancer treatment)	**Learn More**
National Foundation for Cancer Research's Practical Tips and Resources for Cancer Caregivers	**Read**
The Care Partner Project's Must-Have Checklists for Family Caregivers	**Read**

Recommended Resources (cont.)

BOOKS

Stand By Me: A Guide to Navigating Modern, Meaningful Caregiving by Allison J. Applebaum, PhD	**Get**
Zen Caregiving: How to Care for Yourself While Caring for Others by Roy Remer	**Get**

PODCASTS

Caregiver Breathing Room	**Listen**
I Saved You. Now, Do the Dishes	**Listen**
The Cancer Caregiver	**Listen**
The Caregivers Podcast With Dr. Mark Ropeleski	**Listen**

WEBINARS & VIDEOS

American Cancer Society's Caregiver Support Video Series	**Watch**
Bright Spot Network's Realistic Self-Care for Caregivers	**Watch**
Cancer Support Community's Bridging the Gap: Navigating the Practical Challenges of Cancer Caregiving	**Watch**
TED Talk: How to be a Better Caregiver for Cancer Patients by Josh Bedingfield	**Watch**
Triage Cancer Presents: Supporting Caregivers	**Watch**

SUPPORT GROUPS

AnCan Cancer Care Partners Virtual Support Groups	**Learn More**
Bright Spot Network's Virtual Support Groups for Partners & Cancer Caregivers With Young Children	**Learn More**
CancerCare's In-Person & Online Caregiver Support Groups (Select "Caregiver" in the "Populations" box to filter.)	**Learn More**
Elephants and Tea STEEP for Caregivers of AYAs – Sitting Together in Empathy and Emotional Perseverance Virutal Support Group	**Learn More**
F*ck Cancer and Young Adult Survivors United Virtual Caregiver Support Group	**Learn More**

Recommended Resources (cont.)

SUPPORT GROUPS (CONT.)

Jefferson Health Care for the Caregiver Virtual Support Group (Open to all caregivers; your loved one doesn't have to receive care at Jefferson Health to attend.)	Learn More
Mayo Clinic Caring for the Caregiver Virtual Support Group (Open to all caregivers; your loved one doesn't have to receive care at Mayo Clinic to attend.)	Learn More
NY Zen Center Care for Caregivers Virtual Support Group	Learn More

CAREGIVER RETREATS

Camp Mak-a-Dream Caregivers Retreats	Learn More
Dear Jack Foundation's Breathe Now Couples Retreat for Cancer Survivors and Their Significant Others	Learn More
Family Caregiver Alliance Caregiver Retreats	Learn More

ORGANIZATIONS

CancerCare	Learn More
Cancer Support Community	Learn More
Caregiver Action Network	Learn More
Caring Across Generations	Learn More
Cocktails & Caregivers	Learn More
Family Caregiver Alliance	Learn More
FORCE	Learn More
National Alliance for Caregiving	Learn More
Zen Caregiving Project	Learn More

ADOLESCENT AND YOUNG ADULT (AYA) CAREGIVER RESOURCES

Stupid Cancer's AYA Caregiving Hub	Read
Stupid Cancer's AYA Caregiving Resource Guide	Read

Recommended Resources (cont.)

PEDIATRIC CANCER CAREGIVER RESOURCES

American Cancer Society: How to Cope if Your Child Has Cancer Resource Page	**Read**
My Child's Cancer	**Learn More**
The Ahmad Butler Foundation	**Learn More**

BIPOC CAREGIVER RESOURCES

Caregiver Action Network's BIPOC Caregivers Resources and Support	**Read**
Caregivers of Color Collective	**Learn More**
Mental Health America's Caregiving in BIPOC Communities	**Read**

LGBTQIA+ CAREGIVER RESOURCES

Cancer Connection Queer Cancer Affinity Group (Hybrid)	**Learn More**
LGBTQ Caregiver Center	**Learn More**
LGBTQ+ Healthcare Directory	**Read**
The Cancer Network	**Learn More**
UC San Diego Health LGBTQ Cancer Support Group (Open to the community; you or your loved one don't have to receive care at UC San Diego Health to attend.)	**Learn More**

SOCIAL MEDIA ACCOUNTS WE LOVE

Ai-jen Poo / @aijenp	**Follow**
Care Out Loud / @wecareoutloud	**Follow**
Caring Across Generations / @caringacrossgen	**Follow**
Charlotte Bayala – The Cancer Caregiver Podcast / @cancercaregiverpodcast	**Follow**
Imerman Angels / @imermanangels	**Follow**
Neal K. Shah / @nealkshah	**Follow**

Recommended Resources (cont.)

GENERAL

AARP's Caregiver Support Hub	Read
American Cancer Society's Caregiver Resource Guide	Read
Archangels' Caregiver Resources Page	Read
b-present's Understanding and Preventing Caregiver Burnout	Read
Call for Caring Caregiver Toolkit	Read
Cancer Nation's Caring for the Caregiver: Cancer Survival Toolbox	Read
Cancer Support Community's 10 Tips for Navigating Relationships and Communication as a Caregiver	Read
Caregiver Action Network's Family Caregiver Toolbox	Read
Care Out Loud's Caregiver Resources & Tools	Read
Caring Men's Guide for Male Caregivers	Read
Family Caregiver Alliance's Caregiver's Bill of Rights	Read
Family Caregiver Alliance's Caregiver Resource Hub	Read
Family Caregiver Alliance's Taking Care of YOU: Self-Care for Family Caregivers	Read
Hospice Foundation of America: The Difference Between Hospice and Palliative Care	Read
Mount Sinai Steven S. Elbaum Family Center for Caregiving Resources Page	Read
National Alliance for Caregiving's Caregiving Without a Roadmap: Insights from Cancer Caregivers	Read
NCCN's Caregiving for People With Cancer	Read
Stanford University Framily (Friends & Family) and Mental Health Lab	Read

GRIEF & BEREAVEMENT

Imerman Angels Grief Toolkit	Read
All There Is With Anderson Cooper	Listen

Recommended Resources (cont.)

GRIEF & BEREAVEMENT (CONT.)

Good Grief Podcast	**Listen**
Good Grief Resources	**Read**
Good Mourning Podcast	**Listen**
TED Talk: We Don't "Move On" from Grief. We Move Forward With It by Nora McInerny	**Watch**
The Healing Center	**Learn More**

RECURSOS EN ESPAÑOL

Cancer Support Community Cuidadores	**Leer**
Cancer Support Community Cuidando a los Padres	**Leer**
CaringInfo Cuidado Médico Anticipado	**Leer**
Imerman Angels Kit De Duelo	**Leer**
Programas y Servicios de la American Cancer Society	**Aprender Mas**

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Interview with Jemma Cabral – July 6, 2026

Interview with Ranak Trivedi, PhD – April 16, 2026

Interview with Scout – March 19, 2026

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