



THE CAREGIVER'S GUIDEBOOK

Helping you navigate the journey with information, strategies, and support.



NOVARTIS



CREATED IN PARTNERSHIP WITH THE NATIONAL ALLIANCE FOR CAREGIVING

“Where there is love
there is life.”

.....

MAHATMA GANDHI

It can happen in an instant

Your loved one received the diagnosis. And just like that, both of your lives are forever changed. Your loved one now begins one of the most challenging journeys of his or her life.

But your journey begins, too. In what seems like overnight, you have become the emotional supporter and physical care provider. You're also the decision maker, the researcher, and the bill payer. You must navigate insurance bureaucracy and take care of legal matters. You may be required to administer medicine, aid in transportation, and be available around the clock, 365 days of the year.

You are now a Caregiver.

Get more of the support you need with the Novartis forCare™ app



Download forCare for iOS in the App Store
today!

A GUIDEBOOK TO SUPPORT YOU

Caregivers are the backbone of our society—offering love, support, medical assistance, long-term care, and more to the people they care for.

YOU ARE AN ADVOCATE

You, more than anyone, best know the people you are caring for. You are the person who will fight for them, turn over every stone for them, and always be there for them. Their well-being really does depend on your well-being. We know this, and that’s why this book is for you, the Caregiver.



In partnership with hundreds of Caregivers, we have created this guidebook to empower you along this journey.

THIS GUIDEBOOK WILL:

- ✓ Tell you what to expect along the way
- ✓ Give you helpful strategies to cope with challenges
- ✓ Provide you with tools and tips to successfully manage the day-to-day activities and tasks of caregiving

LOOKING AHEAD

The road ahead of you may seem like a daunting one, but the care you are about to provide to someone special in your life is remarkable and life-changing in many positive ways.

So take comfort in the knowledge that there are things that you can do right now that may help to make your journey a much smoother one.

You Are Not Alone

We are a nation of about 44 million family Caregivers. On average, we're spending 20 hours a week caring for others.



million American adults serve as Caregivers

40%*
men



60%*
women

* AMONG ALL ADULTS, THE PERCENTAGE WITHIN EACH GROUP WHO CARE FOR SOMEONE.

RACE PLAYS NO FACTOR:

6% 62% 13% 17% 2%

Asian

White

Black

Hispanic

Other

85%

of Caregivers care for a relative

Caregiver ages range across the board:

24% 18-34

23% 35-49

34% 50-64

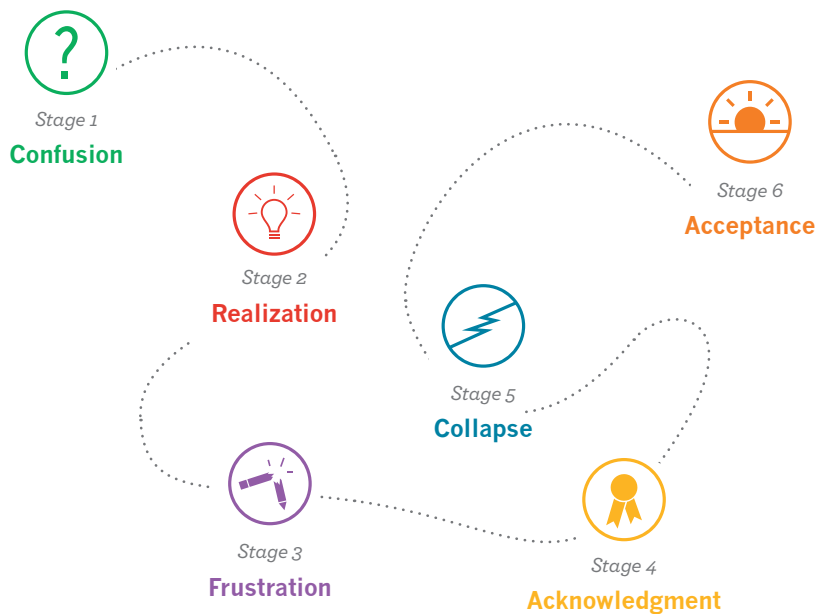
12% 65-74

7% 75+

The Caregiver Journey

Creating a better life for Caregivers is essential. Your journey can be likened to an emotional roller coaster; experiencing the highest of highs and the lowest of lows—without warning, time and time again.

There are 6 emotional stages that we will highlight in this guidebook.



Some Caregivers' experiences will look like a linear journey. But for many, it will look more like jumping forward, stepping back, and jumping forward again—revisiting emotional stages in no particular order.

ACHIEVING A “STEADY STATE” ALONG THE JOURNEY

It’s important that Caregivers learn how to smooth out the bumps to make caregiving a more level journey, so they can be prepared in stressful times. Rather than fighting the highs and lows, caregivers can expect and be ready for them. With planning, you can manage the stress of caregiving through emotional awareness.

“**Steady-State Caregiving**” is a philosophy and a system designed to help Caregivers, including you, find stability when so much around you is changing.

You can’t fight the highs and lows. What you can do is expect and prepare for them.



Confusion

A Caregiver's Journey

.....
 “When my loved one was diagnosed,
 all I felt was loss. Every one of my senses
 was overloaded—I was overwhelmed
 with questions I couldn’t answer, but
 I didn’t know where to go for help.
 I felt numb, spacey, unfocused, and
 frightened. This was bigger than me...
 it was too much for me to handle.”

Stage 1

Confusion



How You’re Feeling

INFORMATION OVERLOAD

After receiving the initial diagnosis, you may find yourself feeling overwhelmed by all of the information being hurled your way. This may lead you to rely on doctors and nurses to filter out the most important information.

HURRIED HANDOFFS

In the chaos of it all, you may also feel like the doctors and nurses didn’t take the time to properly loop you in on arrangements and treatment routines.

UNSPOKEN ARRANGEMENTS

In some cases, you may even experience guilt, shame, remorse, or regret over never having discussed the possibility of your family member or friend needing care, and what that would mean for your relationship.

INVISIBLE

As you care for someone else, you may neglect your own work, social life, family, or financial needs. Who cares for you?

A Caregiver’s Journey

“I felt unprepared to make decisions, and needed to know everything possible about her condition ASAP.”



Be on the lookout for...

TROUBLE MAKING SENSE OF IT ALL

With the hugeness of your new responsibility, you want to be sure you're ready to make informed decisions. But with so much information out there, and with a lot of it written in complicated medical language, you may need help making sense of it.

“At this point, I wasn’t thinking about myself as a ‘Caregiver.’ I was too busy looking for information to think about what my new role meant.”

Tips & Tools



TIP 1: Build Your Care Team

- Begin identifying your core care team: from health care professionals to your personal support network. Keep their contact info at hand—these are the people you’ll turn to throughout your journey.

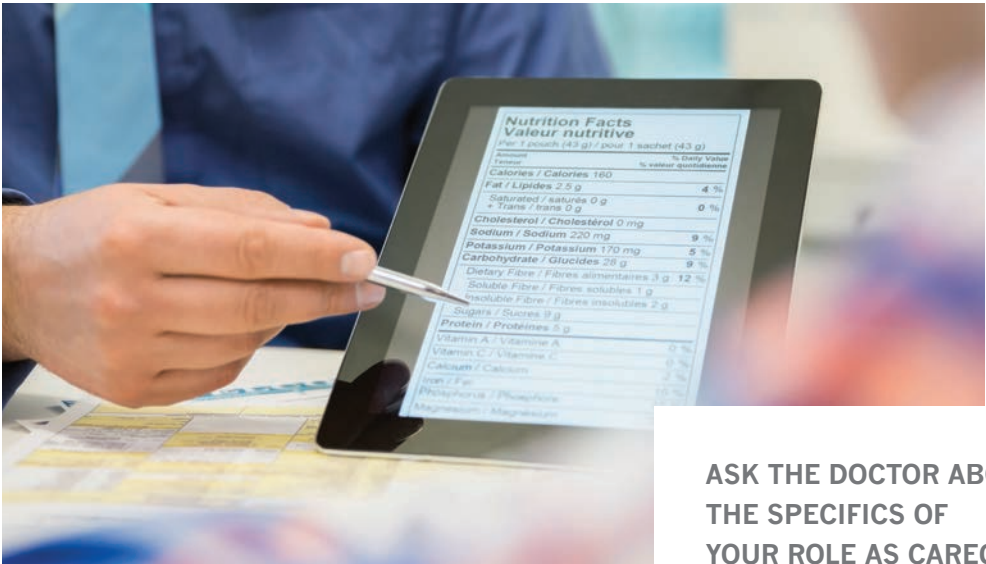
Health Care Professionals

- ☐ Doctors
- ☐ Nurses
- ☐ Social Worker
- ☐ Home Care Attendant
- ☐ Pharmacist
- ☐ Speech/Physical Therapist
- ☐ Mental Health Practitioner
- ☐ Other _____

Personal Support Network

- ☐ Family Member
- ☐ Additional Family Members
(They’re that important)
- ☐ Friends
- ☐ Colleagues
- ☐ Neighbors
- ☐ Legal or Financial Professional
- ☐ Faith Community
- ☐ Other _____

Once you’ve identified your care team, record their contact information on **pages 107 and 108** and keep it close by.



Remember, there's no such thing as a dumb question when it comes to caregiving. So don't be shy.

ASK THE DOCTOR ABOUT THE SPECIFICS OF YOUR ROLE AS CAREGIVER.

Find out what's expected of you in terms of monitoring symptoms, helping with medications, and emotional support. Prepare a checklist of your questions.

“But when I did think about myself, I worried I’d have to deconstruct my whole life to care for my loved one, and then I felt guilty for even thinking that way.”

WHAT TO DO WHEN...

The person you care for may initially refuse your help and resist your role as a Caregiver. If this happens, here are some tips that may help:

- **Introduce changes slowly**
Give your loved one time to accept the idea, and remember that change is hard for everyone.
- **If at first you don't succeed, try again**
If you feel shut down, wait 15 minutes and then try to suggest your idea again.
- **Help your loved one to not feel cut out of the process**
Assure your loved one that he or she should and will still be very involved in care decisions.
- **Offer a trial period for changes such as a home health aide**
Suggest a 2-month trial and then revisit the issue.
- **Reframe additional help as something that will help you as Caregiver**
For example, a home care aide can help do grocery shopping for you.



TIP 2: Know Your Rights

- Consider asking the person you care for to complete a **Health Insurance Portability and Accountability Act (HIPAA) release form** authorizing you to have access to his or her protected medical records. This will allow doctors and other important health care providers to share medical information with you.

Obtain a HIPAA release form online at: https://www.americanbar.org/content/dam/aba/administrative/law_aging/samplehipaaaauthorizationformforfamilymembers.authcheckdam.pdf, or ask your medical provider for more information.

- Consider asking the person you care for to complete a **health care proxy form** so that you can make medical decisions on behalf of him or her, if necessary. Please search online for your state's version of this form.
- Health care professionals can also offer their services to caregivers. They can help you with chronic care management and be reimbursed through Medicare.

Get more information here: <https://www.cms.gov/Outreach-and-Education/Medicare-Learning-Network-MLN/MLNProducts/Downloads/ChronicCareManagement.pdf>

- Did you know some states have enacted the **Caregiver Advise, Record, Enable (CARE) Act**? The CARE Act requires hospitals to recognize the vital role of Caregivers when care recipients are admitted to a hospital (and after being discharged) by providing Caregivers with resources, training, and information to ensure that discharge plans are carried out successfully.

For more information or to find out if your state provides such a benefit, visit: <http://blog.aarp.org/2016/06/07/stepping-up-to-support-family-caregivers/>



TIP 3: Seek Out Community Resources

- There are special support services available to **veterans** and their Caregivers. If applicable, find out what services your loved one qualifies for if he or she is a veteran.

The US Department of Veterans Affairs Caregiver Support Program provides links to numerous resources at: <https://www.caregiver.va.gov>

- Disease-specific foundations are a reliable and informative way to learn about the ins and outs of managing a specific condition or disease, such as heart failure. Often these foundations have materials tailored to Caregivers.

See **pages 115 and 116** for a list of foundations that can help.

- **Area Agencies on Aging** provides caregiver services to those caring for older adults and adults with disabilities. Find participating programs by calling the Eldercare Locator at 800-677-1116 or visiting: <http://www.eldercare.gov>.

“Later that night, I was thinking about the fact that most journeys start with hope and excitement, but this one just filled me with dread.”



TIP 4: Manage Medication

46%

of Caregivers
give pills or
injections to the
person receiving
care

- Ask your doctors or pharmacist medicine-related questions, such as:
 - What is this medicine for?
 - When/how is this medicine taken?
 - How does the drug work?
 - How do I monitor if the drug is working or not working?
 - What if there are issues with the medication?
 - What are potential side effects?
 - How do I know if the person I am caring for is experiencing a side effect?
 - Is this drug brand-name or generic?
 - Will a generic work in place of this brand-name medication?
 - Is this medicine safe to take with the other drugs that he or she is currently on?
 - Is there a way to minimize the number of medications or supplements?
 - What alternative therapies are available?
- Ask doctors or pharmacists for guidance on how to best organize medications.

You can record medications starting on **page 109** to keep as a reference, especially when speaking with the health care team.

CAREGIVER’S CHECKLIST

To summarize, these key tips and resources will help you along on your caregiving journey:

- ☐ Identify a core care team of health care professionals (doctor, pharmacist, social worker) and personal supporters (family, friends, neighbors). Keep their contact information handy.
- ☐ Request that the person you care for complete a health care proxy form and HIPAA release form.
- ☐ Find out if your state has enacted the CARE Act, which guarantees Caregivers certain rights upon hospital discharge.
- ☐ Contact disease-specific foundations for educational materials.
- ☐ Ask the doctor, nurse, or pharmacist questions you may have about medication routines, side effects, and generic alternatives.

Coping With Confusion

It's hard to focus on anything when you're feeling confused. But in order to think critically and clearly, it's important to get your mind in the "Steady State." That often means reducing your feelings of distress and increasing your sense of peace and calm.

When you're feeling confused, try to follow any of the stress-reducing techniques in the IMPROVE the Moment activity. Practicing these exercises—at home or in the doctor's office—takes only a few minutes out of your day but can make a huge difference in the way you feel.



ADVICE
FROM THOSE
WHO KNOW

"It's important to care for yourself as you also care for your loved one. Developing the habit of practicing short stress-reduction exercises when you are feeling confused will help you stay fueled up over the course of the journey. It's about small steps that go a long way."



EXERCISE: IMPROVE the Moment

Instructions: Here are 7 **IMPROVE the Moment** exercises. Feel free to practice all of them, or the one or two that work best for you.

IMAGERY Picture a place you feel happy, safe, relieved, or relaxed. For example, a beach, a hike, a warm, comfortable couch, a time when a crisis will be solved.

MEANING Think about what your role as a Caregiver can do for you. What will you get out of it?

PRAYER Take quiet time to connect mentally with the things that are most meaningful to you, whatever they may be (both spiritual or not).

RELAXATION The goal is to reduce suffering by removing physical stress from the body. You can practice progressive relaxation by tightening each part of your body fully for 5 seconds and then completely relaxing it, starting at the toes first and working your way up through the body. Or, engage in muscle-relaxing exercises such as walking or yoga.

ONE THING IN THE MOMENT Bring all of your attention to what is happening in the moment. Let go of your thoughts about the past and future. Describe (in your mind, out loud, or in writing) what you notice in this moment to bring your attention just to the present.

VACATION Take a small vacation: deliberately step away from your routine temporarily to do something more relaxing, fun, or peaceful. For example, order takeout instead of cooking, or take a nap!

ENCOURAGEMENT Be your own cheerleader. The goal here is not to be overly optimistic about your situation but to encourage yourself to stick with it and tell yourself you will succeed.





Realization

A Caregiver's Journey

“After the initial shock wore off, I started to realize that things wouldn’t be returning to normal. I hesitantly gave in to this reality and tried to focus my energy on new plans, new routines...a new normal for the two of us. This made me feel somewhat relieved, but I was still terrified of what being a Caregiver would really mean.”

Stage 5 Collapse	Stage 6 Acceptance	Parents & Spouses	Important Resources
Introduction	Stage 1 Confusion	Stage 2 Realization	Stage 3 Frustration
			Stage 4 Acknowledgment

Stage 2

Realization



How You’re Feeling

“I’M NOT A CAREGIVER”

At this point, you may start to think of yourself as “just a spouse/daughter or son/parent doing what anyone would in this situation.” Caregiving is seen as a natural extension of an existing relationship.

ROLE BREAKING & MAKING

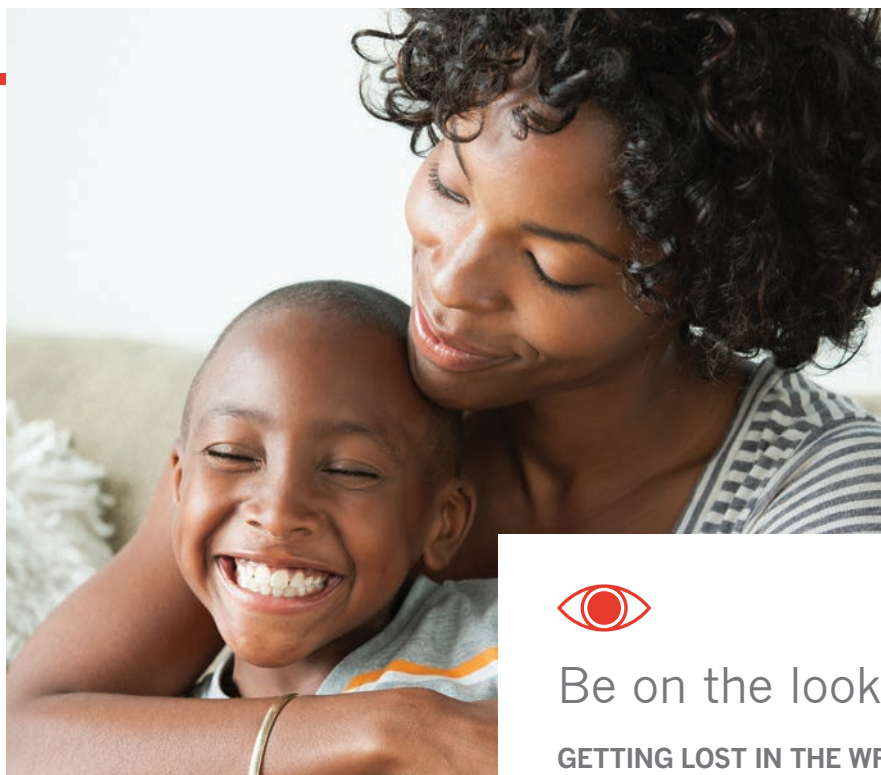
You’re not the only one with a new role. The entire family often has parts to play, as medicine patrollers, therapists, and more.

DOCTOR DUTIES

You may even find yourself taking on many medical-related responsibilities, but feel anxious that you’ll do something wrong or harmful by accident.

A Caregiver’s Journey

“I tried to push the emotions aside and stay as rational as I could. After all, if I didn’t start making some decisions and progress for her, who would?”



Be on the lookout for...

GETTING LOST IN THE WRONG RESOURCES

You may find yourself struggling to access the information you need to act confidently, or wasting time on resources that don't help. With so much to wrap your head around in a short amount of time, you may need assistance locating relevant and simple resources.

“Even though the situation wasn't ideal, I felt a new wave of appreciation for her and for our relationship.”

Tips & Tools



TIP 1: Build Your Care Team

- Call the insurance company of the person you are caring for to learn about coverage for home health care services (such as aides to help with routine hygiene). Keep a record of each call for future reference.
-
- See **pages 113 and 114** for a call log that you can use.
-
- Consider speaking with your employers about your caregiving situation. Looping them in early on can reduce later stress in the case of unforeseen emergencies or absences.

It's a Family Affair

Caregiving doesn't only affect your life and that of the person you care for. It impacts the entire family. Siblings and relatives that you may not be very close to suddenly re-emerge to help create a circle of care.

And with help often comes conflict. Finances, opinions on care, and long-term planning become hot topics. Emotions run high, and old conflicts resurface. But there are actions you can take to help make peace during the caregiving journey, while giving you the support you desperately need.

- Remember that this is a difficult time for everyone. Try to have compassion for your family members, even if you don't agree with them.
- Ask specifically for what you need from them directly without the use of guilt or anger.
- And when all else fails, bring in an objective professional, such as a family counselor, to help solve conflicts.

Tips & Tools



TIP 2: Know Your Rights

- Refer to **A Caregiver’s Bill of Rights**, below, when you need assurance or support for all you do:

A CAREGIVER’S
BILL OF RIGHTS

By Jo Horne

I have the right:

To take care of myself. This is not an act of selfishness. It will give me the capability of taking better care of my loved one.

To seek help from others even though my loved ones may object. I recognize the limits of my own endurance and strength.

To maintain facets of my own life that do not include the person I care for, just as I would if he or she were healthy. I know that I do everything that I reasonably can for this person, and I have the right to do some things just for myself.

To get angry, be depressed, and express other difficult feelings occasionally. To reject any attempts by my loved one (either

conscious or unconscious) to manipulate me through guilt and/or depression.

To receive consideration, affection, forgiveness, and acceptance for what I do, from my loved ones, for as long as I offer these qualities in return.

To take pride in what I am accomplishing and to applaud the courage it has sometimes taken to meet the needs of my loved one.

To protect my individuality and my right to make a life for myself that will sustain me in the time when my loved one no longer needs my full-time help.

To expect and demand that, as new strides are made in finding resources to aid physically and mentally impaired persons in our country, similar strides will be made towards aiding and supporting Caregivers.

Tips & Tools

- If applicable, make sure you learn the basics of Medicare. Confirm that your loved one's coverage is appropriate, or investigate options for alternative or additional coverage.

To learn more, visit: <https://www.medicaremadeclear.com/choosing-plan>

- Determine if your loved one needs assistance with legal affairs. Contact an attorney for advice regarding a living will and testament (as well as a health care proxy, if you haven't yet done this). It's never too early to prepare, even if it seems unnecessary at the time.

To learn more, visit: <http://www.caringinfo.org/i4a/pages/index.cfm?pageid=3284>

- Also consider a power of attorney document to ensure that your loved one's care is not disrupted for financial reasons. Speak with a lawyer for more information.

“I realized that other problems in my life suddenly seemed silly and unimportant. I felt sad for her, but happy that I could help her in some way.”

Tips & Tools



TIP 3: Find Financial Assistance

Keep a list of the whereabouts of important documents, files, and accounts. The form on **pages 105 and 106** can help.

- Did you know that medication manufacturers may offer financial assistance? Call the pharmaceutical company to inquire about financial support programs or co-pay cards that can lessen your out-of-pocket costs. Refer to the medication bottle or pamphlet for the name of the manufacturer.
- Consider talking to the person you care for about expectations for your Caregiver role. For instance, who will be responsible for items not covered by insurance? Take into account the costs of special dietary requirements, toiletries, home goods, transportation, orthopedic and prosthetic devices, and other day-to-day costs. Clearly defining these responsibilities early may help prevent tension later on.
- Caregivers can contact their county or state **Department of Health and Human Services** for financial programs that may provide assistance with acquiring health insurance and prescription medications.
- Discuss the status and responsibility for the financial accounts of the person you care for. Determine together whether you should have access to his or her:
 - Checking account
 - Savings account
 - Other assets (stocks, bonds, etc)
 - Real estate and other property documentation
 - Safety deposit box/security box or home safe

Tips & Tools



TIP 4: Seek Out Community Resources

- If you are caring for someone who is older, check out your local **Area Agency on Aging**. This group can point you to caregiving resources available in your community. These agencies are well connected to numerous services and should be able to refer you to the people or organizations you need. (This site is also useful even if you are not caring for someone who is older.)

To learn more about the Area Agency on Aging, visit: <https://www.n4a.org>

- The **Home Alone Alliance** has a collection of free training videos for caregivers—which were created by several different national caregiving organizations.

To take a look at the video library, visit: <http://www.aarp.org/ppi/info-2017/home-alone-alliance.html>

Tips & Tools



TIP 5: Manage Medication

- Many people simply fail to take their medication because they can't remember to. Help yourself and the person you care for with medication management using techniques/tools such as:
 - A pill organizer
 - Electronic reminders
 - Combining with a daily task, such as making coffee or brushing teeth
 - Combining with a self-care ritual that might include having a cup of tea, meditating, or reading the news
 - Setting an alarm
 - Suggest saying out loud, *"I am taking my medicine now"* as a way to develop the habit of remembering to take medication
 - Keeping medication visible, perhaps out on a kitchen counter (if there are no small children in the home)
 - Enlisting your loved one's help. Have your loved one take meds when you are on the phone with them, or while you're together

CAREGIVER’S CHECKLIST

To summarize, these key tips and resources will help you along on your caregiving journey:

- ☐ Contact your loved one’s insurance company to find out about home health aide coverage and options.
- ☐ Refer to **A Caregiver’s Bill of Rights** when you feel uncertain.
- ☐ Contact an attorney for advice regarding legal affairs, including a **living will, power of attorney, last will and testament, and planning for aging adults with disabilities.**
- ☐ Contact the medication manufacturer to inquire about financial assistance programs.
- ☐ Contact your local **Area Agency on Aging or Aging and Disability Resource Center** for information on community resources.
- ☐ Try medication-management techniques such as using pill organizers, electronic reminders, alarms, or the Medication List (**pages 109 and 110**) to see what works best for both of you.
- ☐ Look for available resources through the **National Council on Aging’s** Benefits Checkup at: <https://www.benefitscheckup.org>.

Achieving Realization

During this stage, it can be easy to focus on the negatives of what your new caregiving role means and how it may drastically affect your life. This is normal and completely understandable.

But coming to a healthy realization requires you to look at things differently. Instead of noticing what has changed for the worse, it's better to focus on what has improved, or even on what has simply stayed the same. Even though it may feel like your life has completely changed, there can be comfort in realizing how much has stayed the same.

”

ADVICE
FROM THOSE
WHO KNOW

“Shifting the way you think about change doesn’t take away the pain of what’s going on. However, building the mental and emotional skills to focus on what’s the same and what’s getting better can help you take a bird’s-eye view of the full picture of your life.”



EXERCISE:

Looking at the Glass Half Full

Instructions: In the boxes below, answer the 3 questions about the changes you’ve undergone since becoming a Caregiver.

Do any of your answers surprise you?

What has changed?

Example: Since becoming a Caregiver for my youngest child, I’m now only able to work part-time.

What stayed the same?

Example: I’m able to go to my weekly book club meeting thanks to my husband watching the kids.

What has improved?

Example: We’ve brought in a home health aide on Mondays and Fridays to relieve some of the pressure on me.





Frustration

A Caregiver's Journey

“Things finally seemed to be settling down. We figured out a new routine, I started to get my life back on track, and then...boom! Just like that, her condition seemed to get worse. I didn't know why. Was it the medication? The natural progression of the disease? Some failure on my part?”

Stage 5 Collapse	Stage 6 Acceptance	Parents & Spouses	Important Resources
Introduction	Stage 1 Confusion	Stage 2 Realization	Stage 3 Frustration
			Stage 4 Acknowledgment

Stage 3

Frustration



How You’re Feeling

SELF-REFLECTION

Here you may start to think more about what the role of a Caregiver means, and you may often find yourself battling conflicting emotions about the impact of caregiving on your own life. You may be realizing that your caregiving journey could last for several years.

LEANING ON OTHERS

This is the point at which you’ll begin to lean on friends, family, and other sources of support more than before as you recognize that this is now vital for surviving the journey.

MEDICAL PARTNERSHIP

This is also when you and your loved one will take time to identify a doctor who serves as a true partner and advocate. The doctor, the person being cared for, and the Caregiver form a treatment team to make more informed decisions moving forward.

A Caregiver’s Journey

.....

“I felt blindsided and unprepared for the sudden turn for the worse. It took me right back to when we first found out she was sick.”



Be on the lookout for...

Every day can start to feel the same: another round of issues to tackle and repetitive needs to address. Having to focus mainly on managing the day-to-day tasks of caregiving may make it difficult for you to find the time and effort required to plan ahead, or even just to catch up.

“All of those feelings of being overwhelmed, frightened, and confused came shooting back to me, weighing me down.”

Tips & Tools



TIP 1: Build Your Care Team

- Most hospitals and medical offices have a nurse’s hotline that you can call with medical questions. This is a useful resource in cases when you’re uncertain whether the person you care for needs more serious or urgent care. Your insurance company may also offer a hotline for medical questions.
- Your pharmacist is a great source of trusted information about managing medications. Call or visit your local pharmacy if you have questions concerning treatment, especially if you struggle to get your loved one to stick to a medication routine. The pharmacist may be able to offer alternate forms or advice.
- Put a copy of the care recipient’s medication list somewhere that is easily accessible:
 - Hang it on the refrigerator or bulletin board
 - Store it in your wallet
 - Hand out copies to relatives, friends, or a trusted neighbor
 - Take a photo of the medication bottles or list and keep the picture in your phone
 - You can write out a list of all medications your loved one is taking on **pages 109 and 110**
- If you are caring for someone who is far away, gather a list of resources from your loved one’s neighborhood so that you always know whom to call. You can do this by either searching the Internet or simply having a copy of the phone book for your loved one’s city or town.

Tips & Tools



TIP 2: Know Your Rights

- If you are caring for someone who is far away and has difficulty managing daily activities, consider installing a video monitoring system (with permission from the person you care for, of course). These cameras can monitor daily activities and provide you with updates on your smartphone, tablet app, or the Web to let you know how they are doing.

For other tech support options for long-distance Caregivers, visit: <https://www.consumerreports.org/cro/news/2015/05/tech-support-for-long-distance-caregivers/index.htm>

- The **Family and Medical Leave Act** provides eligible employees with up to 12 weeks of unpaid, protected leave each year to care for an immediate family member with a serious health condition. Speak with your HR department or employer to find out if this is an option for you.

Some states, including California, New Jersey, and Rhode Island, provide paid leave for family and medical concerns. Others offer disability insurance. Learn more at: <https://www.dol.gov/whd/fmla/employerguide.htm> and <http://www.ncsl.org/research/labor-and-employment/state-family-and-medical-leave-laws.aspx>

Tips & Tools



TIP 3: Care for Yourself

- Research techniques for calming yourself during stressful times when it’s necessary to concentrate.

TRY THIS RIGHT NOW...

Abdominal or diaphragmatic breathing is a simple activity that can help you stay focused.

As you inhale, breathe in through the nose, encouraging the diaphragm to flatten out and the ribs and stomach to flare out. Your exhale should be longer than your inhale and completed through pursed lips.

-
- Take a break by taking a walk when you’re feeling overwhelmed by decisions. Fresh air and a change of scenery often spur creativity and may help you solve some of the many issues you are facing. Even better, go on a walk with a friend.

“Luckily, I was better prepared to face those feelings this time. I knew it was just a matter of figuring out what was happening and where we should go for help.”

Tips & Tools



TIP 4: Plan for the Unexpected

- Keep a complete file of your care recipient’s medical history, medications, dosages, and emergency medical contacts on hand so you have quick access in times of urgent changes (see **pages 105–114**). Additionally, keep a notebook to record doctor visits and phone calls, as well as a place to store resources. Carry a folder with all important papers such as a medication list and health care proxy.
- If the person you care for is hospitalized, discharge can often be abrupt and chaotic. When presented with discharge papers, be sure to ask the hospital doctor/nurse the following questions:
 - Have medications changed?
 - Are there any limits on physical activity?
 - Are there any foods/liquids to be avoided?
 - Is physical or occupational therapy required?
 - What is the name/contact information for a hospital social worker who can assist with references for visiting nurse services, home health aides, housecleaning services, etc?
- Be sure to schedule a follow-up with the primary doctor/specialist immediately following discharge from the hospital to discuss any changes to your loved one’s life.

“I didn’t feel quite as hopeless, but I did feel frustrated by this sudden turn for the worse.”

CAREGIVER'S CHECKLIST

To summarize, these key tips and resources will help you along on your caregiving journey:

- ☐ Rely on the local pharmacist and your medical office's nursing line for questions regarding changes in symptoms or difficulties adhering to medication routines.
- ☐ Keep copies of the medication list easily accessible and on hand at all times.
- ☐ Keep all medical documents in a binder, complete with emergency contacts and space to log doctor visits.
- ☐ Speak to your workplace's HR department about eligibility for the Family and Medical Leave Act and whether paid leave is available.
- ☐ Find relaxation techniques that work best for you, such as taking a brief walk or journaling.
- ☐ If you are a long-distance Caregiver, gather a list of the important contacts from your loved one's neighborhood.
- ☐ Prepare a list of questions for hospital staff to ask during a hospital stay and when preparing for hospital discharge.
- ☐ If the person you care for develops physical limitations, assess the safety and accessibility of the home he or she will return to after the hospital stay.

Dealing With Frustration

While it's natural to feel frustrated when things take an unexpected turn for the worse, it's not healthy to get caught up in the feeling for too long. Frustration limits your ability to make effective decisions on the spot, which is often needed of Caregivers.

One of the best ways to cope with frustration is by venting constructively. We've all done the bad kind of venting—criticizing or yelling at someone else, maybe even punching the wall. But good venting helps to reduce your feelings of frustration and stress (without collateral damage) and can actually make you feel better afterward. One helpful way to cope with frustration is journaling.

“We now know through scientific studies that when we put our thoughts into words by journaling, stress is reduced and our immune systems are strengthened. Over time, the practice of taking 10 to 15 minutes out of the day to write down what you’re thinking and feeling can be the grains of sand that ultimately turn into the pearl of resilience during difficult times.”

”

ADVICE
FROM THOSE
WHO KNOW



EXERCISE: Write It Out

Instructions:

- 1. Take your “temperature” by circling the number on the scale that best represents how you’re feeling before beginning the journaling exercise.
- 2. Set a stopwatch for 5 minutes. Journal for 5 minutes on the lines below. Grab extra paper as needed.
- 3. Take your “temperature” after completing the journaling exercise.
- 4. Do you feel differently after journaling? Practice this exercise whenever you find yourself feeling frustrated.

Before Temperature



Feeling very calm

Feeling extremely upset

After Temperature



Feeling very calm

Feeling extremely upset





Acknowledgment

A Caregiver's Journey

“I felt like I was finally getting the hang of this ‘Caregiver’ thing and could acknowledge the ups and downs of my new role. In fact, I felt like a caregiving pro...like I could handle anything that came my way. I knew where to turn in times of trouble, and had trusted resources and people to fall back on when I needed to.”

Stage 5 Collapse
Introduction

Stage 6 Acceptance
Stage 1 Confusion

Stage 2 Realization
Parents & Spouses

Stage 3 Frustration
Important Resources

Stage 4 Acknowledgment

Stage 4
Acknowledgment



How You’re Feeling

EXPERT STATUS

Here, you may begin to feel like a walking pill reminder, but you know the routines by heart and are taking ownership over your loved one’s treatment and management. You start to take on a sense of expertise in the disease area.

CAREGIVER GAIN

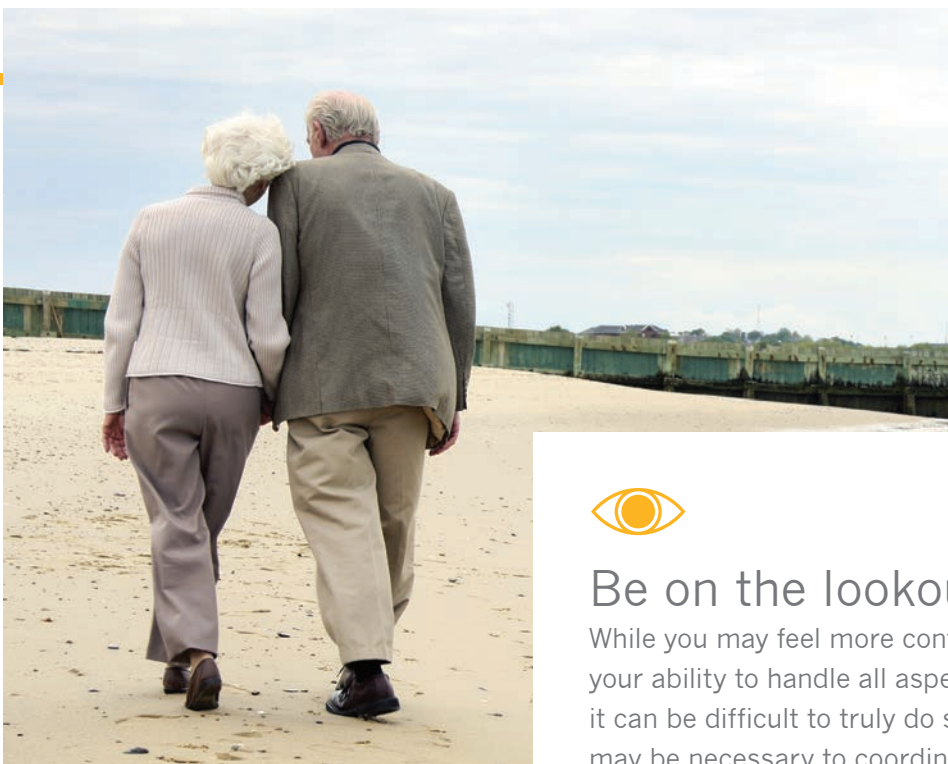
Some research has recognized the idea of “Caregiver Gain,” which is when you start to feel that your own well-being has improved as a result of your new role. Some report a greater sense of meaning and purpose, and improved life satisfaction when caregiving.

CAREFUL OBSERVATION

So as not to interfere with your loved one’s independence, you may instead become more watchful and observant, keeping a close eye on symptoms and signs of decline.

A Caregiver’s Journey

“Yet, I do have to admit, as calm and in control as I felt on the surface, I was struggling with some things inside.”



Be on the lookout for...

While you may feel more confident in your ability to handle all aspects of care, it can be difficult to truly do so, and it may be necessary to coordinate with others. Yet you may be resistant to using outside resources, and you may not trust the help you receive.

“She depended on me and trusted me. I was the only one who understood her needs. But this made me feel like I was the only one who could really help her. It was lonely and sometimes scary, too.”

Tips & Tools



TIP 1: Build Your Care Team

- Use every encounter with your care recipient’s doctors and specialists as an opportunity to learn more about the disease or disability. Nurses are often very adept at pinpointing the stage of progression, and when asked, they are often willing to provide some insight into what to expect.
- Health administrators in hospitals and assisted living facilities also have access to various support services—from a trusted network of live-in nurses to local medical supply companies that offer personal consultations.
- Be sure to ask about special considerations for care if the person you care for has multiple, ongoing health issues (called “chronic conditions”).

Tips & Tools

- Speak with your care team about modifying the care recipient’s home to be safe and secure. An occupational therapist can evaluate the challenges and shortcomings of the home, make modification recommendations, and refer products and services to help make improvements. Ask a doctor for a referral to an occupational therapist in your area.
- If you are caring for an older adult who is in an assisted living facility, schedule conference calls with doctors, the assisted living facility team, or the nursing home staff so that several family members can participate in one conversation and get up-to-date information on your loved one’s health and progress.

Tips & Tools



TIP 2: Manage Medication

- Be proactive about medication refills. Many pharmacies have auto-refill programs that will help you remember when medication needs to be refilled and picked up so you can stay on track.
- Consolidate prescriptions to one pharmacy to stay organized and make medicine pickup more manageable. Programs such as **Align My Refills** can help you identify pharmacies that can synchronize medicines. Learn more at: <https://www.aphafoundation.org/align-my-refills>.

“I tended to blame myself when things went wrong. Despite these feelings, I became aware of how important my role was, and I actually felt a sense of purpose and control in my life that I hadn’t before.”

Tips & Tools



TIP 3: Plan for the Unexpected

- Have the conversation about long-term care with the person you care for and others in the care circle. Consider an outside facilitator to ensure all voices are heard and that emotions don't override all practical decisions. Facilitators can moderate, offer conversation starters, and coach Caregivers through entire conversations.
- Begin financial planning, not just for day-to-day expenses, but also to cover the cost of long-term care. Consider how paying for care may impact your own retirement and future Social Security payments. For planning tools, visit: <https://www.investor.gov/tools/other-resources>
- Determine the existence and location of all insurance policies (medical, disability, house, car, long-term care, life insurance, and veterans insurance).
- Keep a visual record of medications and documents on your smartphone or a camera.
- Need help organizing meals for your loved one?

Investigate how at: <https://www.mealtrain.com>

CAREGIVER’S CHECKLIST

To summarize, these key tips and resources will help you along on your caregiving journey:

- ☐ Reach out to administrators in hospitals or assisted living facilities for a network of support services and medical supply companies.
- ☐ Speak with your care team or an occupational therapist about modifying the care recipient’s home to be safe and secure.
- ☐ Consolidate medication prescriptions to one pharmacy.
- ☐ Enroll in an auto-refill program through the pharmacy to stay on top of refills.
- ☐ Talk to your loved one and other caregivers about long-term care plans.
- ☐ Determine the existence and location of all insurance policies, not just medical ones.

Achieving Acknowledgment

Now that you may be starting to come to terms with your role as Caregiver and have become acquainted with the ups and downs, it's important to acknowledge how much you've grown in the process. Taking the time to appreciate what you've done for your loved one and what you're grateful for will help you continue to improve your own well-being and achieve Steady State.

You can easily create these positive feelings by practicing an exercise called "Growing Gratitude." For a few minutes each day, either write down or think about 3 things that you are grateful for, whether they relate to your caregiving duties or not. They could be anything, small or large, simple or deep.

"Gratitude is contagious. Being grateful for things in your life is about more than just being a thoughtful person. Studies show that people who practice gratitude are happier, more helpful, and more pleasant to be around. Being grateful for the good won't eliminate the illness, but it can help change how you're feeling in the moment on any given day."



ADVICE
FROM THOSE
WHO KNOW



EXERCISE: Growing Gratitude

Instructions: In each of the spaces below, reflect on and write about 3 things you are grateful for today. These could be simple everyday pleasures that you happened to notice, people in your life, personal strengths or talents, moments of beauty, or gestures of kindness. Try to think about these things as gifts you have received in your life, even though we may not normally think of them that way.

1.

2.

3.





Collapse

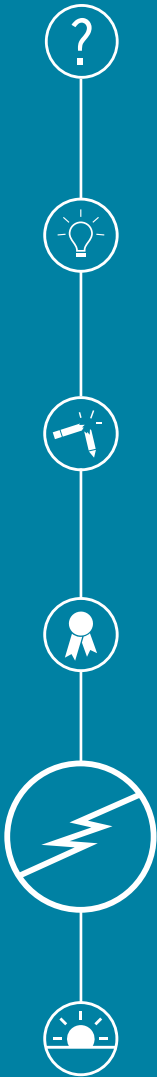
A Caregiver's Journey

.....

“I really believed I had everything in control. She was doing okay, and I had made peace with my new responsibilities as a Caregiver. At least, I thought I had. But there was something I was neglecting the entire time...myself.”

Stage 5 Collapse	Stage 6 Acceptance			
	Parents & Spouses		Important Resources	
Introduction	Stage 1 Confusion	Stage 2 Realization	Stage 3 Frustration	Stage 4 Acknowledgment

Stage 5
Collapse



How You're Feeling

PUTTING YOURSELF SECOND

Sometimes you end up sacrificing your own health for that of the person you're caring for. Sound familiar? Compared with other adults, you have a higher risk of sleep deprivation, immune system deficiency, joint problems, depression, chronic anxiety, and loss of concentration.

TOXIC THOUGHTS

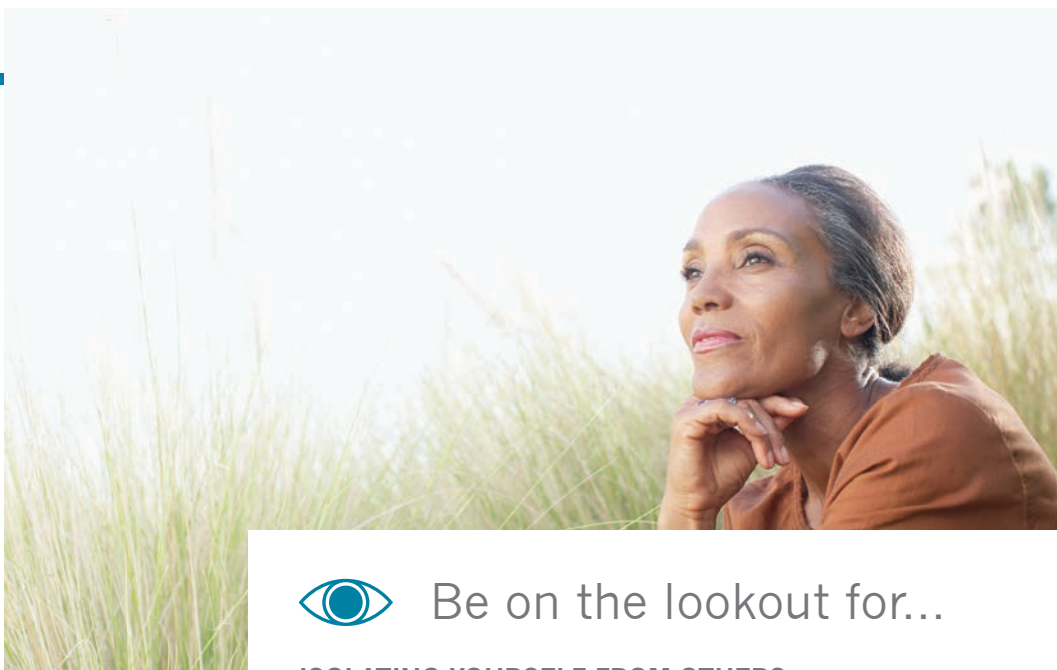
You may even be bottling up those "unthinkable" and "unacceptable" thoughts, preventing honest communication with others, which sometimes creates resentment.

ONE-SIDED CAREGIVING

Caring for family or friends is frequently placed above caring for oneself, making it difficult for you to practice healthy behaviors, such as taking medication properly and exercising. You may need a break, but lack resources or information about how to take one.

A Caregiver's Journey

“It’s like all of a sudden my own physical and emotional needs caught up with me, and I just couldn’t do it anymore.”



Be on the lookout for...

ISOLATING YOURSELF FROM OTHERS

It can be hard to relate to others when you feel as though no one else can truly understand what you're going through. But without a chance to connect and reset with friends and other Caregivers, you may feel more isolated in your caregiving journey.

“I hit a breaking point. The lowest of lows. I was exhausted, broken, depressed and I questioned whether things would ever change or improve. Her health was stable, but now I was the one suffering.”

Tips & Tools



TIP 1: Build Your Care Team

- Join a local Caregiver support group to connect with other Caregivers and learn new tips and tricks for coping, caring, and blowing off some steam. These are frequently offered through disease-specific foundations or your local hospital. You can search online to see which ones are available in your area, or even join a telephone-based support group.
- Online caregiving forums are a good alternative to in-person support groups, providing connection and access to caregiving “life hacks” from the people who know the job best. Forums can be general or disease specific and can be also on Caregiver-focused websites or general social media platforms such as Facebook.
- Consider sharing your caregiving experience as a vocal advocate in your community. This can include becoming a patient advocate at a hospital or joining an outside group, just for Caregivers. Your voice and experience are powerful and can help inform others about the process.

Tips & Tools



TIP 2: Care for Yourself

- Keep your strength up by eating healthy and exercising, even if it seems low priority given all of your new responsibilities. If you're out of good ideas, find new variations of recipes online and choose foods that are in season.
- Consider consulting a trained health or mental health professional if you feel like you may be experiencing symptoms of depression.

To learn more, visit: <https://www.caregiver.org/depression-and-caregiving>

For additional support and resources, visit: <https://www.nami.org/Find-Support>

- Be sure to schedule regular medical care for yourself and report any changes in your health to your doctor.
- Identify other Caregivers who can give you a break by providing care to your friend or loved one. This may include home care aides, volunteers, or eldercare programs in your community.

Tips & Tools

- Alternative therapies, such as art or music therapy, could also help you restore energy, improve mood, and heal your body in the wake of stressful times. Taking a “musical time-out” and listening to some songs is a fast and simple way to calm your breathing and decrease your heart rate, which will make things feel less daunting. The National Center on Creative Aging has a free video series on “creative caregiving” available at: <http://creativecaregiving.creativeaging.org>.
- Color can have a dramatic impact on mood for loved one and Caregiver alike. Red and violet are stimulating colors that can boost energy levels by making the body pump more adrenaline, green and yellow evoke feelings of happiness, and blue makes us feel calm.

“I realized how much I had sacrificed to care for her, how I had neglected my friends, my health, my personal space, and even my other family members. I wondered how it had gotten to this point...how had I not noticed sooner?”

Tips & Tools



TIP 3: Plan for the Unexpected

- Contact local houses of worship (such as churches or synagogues) for assistance. Often, there are volunteers who will stay with ill or aging family members so that Caregivers can take a much needed break, or provide assistance with daily chores such as light food shopping and laundry.
- Some states have organizations that provide respite (a break from your responsibilities) to Caregivers and may even provide in-home visits or day care for children or older adults if your loved one can't be left alone.

To learn more about what's available in your area, visit the **ARCH National Respite Network and Resource Center** at: <https://www.archrespite.org>

- Consider employing a home health aide a few days per week to assist with household chores, transportation, or hygiene-related issues. Understand that home health aides cannot dispense medication; only licensed nurses are able to assist with medication management.

CAREGIVER’S CHECKLIST

To summarize, these key tips and resources will help you along on your caregiving journey:

- ☐ Join a local Caregiver support group or participate in an online support group.
- ☐ Make your health a priority. Join a gym or a fitness class, or search online for nutritious recipes.
- ☐ Consider consulting a trained professional if you feel like you need someone to talk with outside of your friends and family.
- ☐ Schedule regular medical care for yourself.
- ☐ Explore alternative therapies such as art or music therapy to rejuvenate energy and mood.
- ☐ Contact local houses of worship for assistance or support.
- ☐ Make personal time a priority by scheduling time for yourself and opting for in-home care/day-care services if your friend or relative can't be left alone.

Coping With Collapse

At this stage, you may feel like your caregiving duties have gotten the best of you. Understandably, it's hard to pay attention to your own needs when your care recipient's needs are always top of mind.

But it's important during this moment that you take a step back and care for yourself. When you can plan ahead in order to avoid stressful situations or delegate responsibilities to others, you can then free up time to allow yourself to relax, exercise, or do the things necessary to feel rejuvenated and reenergized.



ADVICE
FROM THOSE
WHO KNOW

“Even minimal changes in the way you prioritize things can help you move away from being in crisis mode and closer to being in a mode that lets you plan, delegate, and make time for yourself. Thinking even small things through ahead of time can make a huge difference in your day-to-day feelings of anxiety and happiness.”



EXERCISE:

The Caregiver’s Decision Grid

Instructions: The decision grid can help you manage your time between caregiving and your other responsibilities, so that you have more time for important self-nourishment activities, like those described in this guide. The goal of this grid is to move as many tasks as possible from Box 1 “Do” to Box 2 “Delegate” and Box 3 “Plan.” This allows you to spend more time on Box 4 “Nourish.” Think about your tasks, and fill out the decision grid below.

	Yes	DIRECTLY AFFECTS YOUR LOVED ONE?	No	
URGENT?	Yes	<div><p>1. Do</p><p>Most important tasks. You have to do them now (eg, call doctor about any new symptoms)</p><hr/><hr/><hr/></div>	<div><p>2. Delegate</p><p>Tasks that can be delegated to others (eg, grocery shopping)</p><hr/><hr/><hr/></div>	
		No	<div><p>3. Plan</p><p>Tasks you must plan or they'll become urgent (eg, pick up prescription refill)</p><hr/><hr/><hr/></div>	<div><p>4. Nourish</p><p>Things that you can do for “me time” (eg, go on a jog, do IMPROVE exercises, journal)</p><hr/><hr/><hr/></div>





Acceptance

A Caregiver's Journey

“I spent some time reflecting on my caregiving journey and coming to peace with it. It made me sad to admit to myself that she wouldn’t be getting better; her condition wasn’t going to just go away. But it also made me feel happy, proud, and purposeful to know that I was doing all that I could for my loved one.”

Stage 6
Acceptance



How You’re Feeling

THE POWER OF FORESIGHT

At this point, Caregivers have the power of foresight on their side and know what to expect in terms of symptoms in the future, which often provides a sense of calm and relief.

CONNECTED CAREGIVING

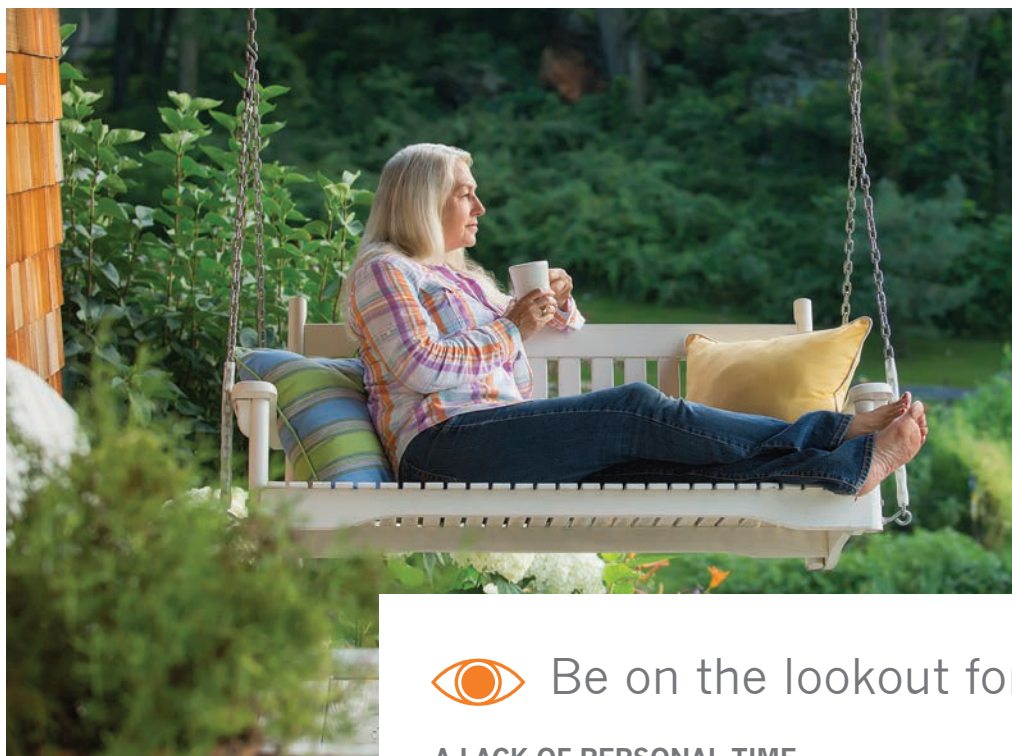
Many Caregivers express gratitude for the ability to connect online with other Caregivers. They use social media, forums, and websites to share their journeys and read about the journeys of others.

A FOCUS ON THE FUTURE

In many cases, the Caregiver is deeply involved in “what’s next” conversations with his or her loved one, other Caregivers, and doctors. Planning of future arrangements is the main focus.

A Caregiver’s Journey

“I found comfort in knowing that I’d have no regrets looking back on this time. It was a relief to accept that I could be a great Caregiver for my loved one—the Caregiver she deserved—but not lose myself in the process.”



Be on the lookout for...

A LACK OF PERSONAL TIME

Taking care of someone can feel “all-consuming”; even when you’re “off-duty,” you feel like you’re constantly “on.” You may feel guilty doing things for yourself and setting aside dedicated “me time,” especially when there is always so much to do.

“I also finally knew how important it was to take care of me. After all, how could I care for someone else if I couldn’t care for myself?”

Tips & Tools



TIP 1: Build Your Care Team

- Use a shared online calendar to keep track of appointments and visits with other family Caregivers. You can use Google Calendar or find similar calendar tools by searching online or in the Apple App Store or Google Play. These shared calendars allow all Caregivers to input their info into a centralized place, making your life easier and more organized.
- Lean on friends and family for support and escape from daily challenges. Carve time into your schedule for social outings or even brief phone calls or video chats.
- Consider joining a local caregiving coalition or patient advocacy group—and participate in events.
- Mobile apps such as **Lotsa Helping Hands** and **Carely** can help organize the care team and improve communication. You can find them in the App Store or online. The **forCare** app is a great tool to manage tasks, keep track of appointments, and find additional support. It also has some tips for making the most of doctor visits with your loved one.



TIP 2: Care for Yourself

- Routines are your friend. Establish a schedule that allows you to check in on your loved one in a way that works for you and set boundaries outside of this schedule. For instance, designate certain days and times for visits or calls. This will make it easier for you to plan things outside of your Caregiver role.
- Consider what types of activities you can do, together with the person you care for. Shared experiences can reduce stress and improve the caregiving experience.

“With this acceptance and all of the knowledge I’d acquired, I was able to move forward with a positive mindset. I focused on preparing myself mentally and emotionally for what was to come, and continued to care for her in the best way I knew how.”

Tips & Tools



TIP 3: Seek Out Community Resources

- Community resources can help with some of the burden of day-to-day routines. Look into organizations such as **Meals on Wheels** or local shared transportation services to see what your community offers.

To learn more about **Meals on Wheels**, visit:

<https://www.mealsonwheelsamerica.org>

For other programs designed to help caregivers, check out the **Eldercare Locator** at:

<https://www.eldercare.gov>



TIP 4: Manage Medications

- Be open to new technologies that could help relieve some of your caregiving duties, including mobile apps and products. For instance, Bluetooth-enabled pill organizers or medication-reminder apps could help your friend or loved one stay on track.

Tips & Tools



TIP 5: Plan for the Unexpected

- Know the difference between palliative care and hospice care. Each care type offers a single program to handle medications, day-to-day care, equipment, bereavement counseling, and symptom treatment. They differ in their care location, timing, payment, and eligibility for services.

To learn more, visit: <http://www.caregiverslibrary.org/caregivers-resources/grp-end-of-life-issues/hsgroup-hospice/hospice-vs-palliative-care-article.aspx>

- Although a difficult subject to talk about, discussing end-of-life care will ensure that your loved one’s wishes are honored when the time comes. Tools such as **Five Wishes**: [\[https://agingwithdignity.org/five-wishes/about-five-wishes\]](https://agingwithdignity.org/five-wishes/about-five-wishes) and the **Conversation Project**: [\[https://theconversationproject.org/\]](https://theconversationproject.org/) can help.
- Address your spiritual needs, as well as those of the person you’re caring for. Make sure you understand the care recipient’s end-of-life wishes regarding religious wants and burial or cremation.
- Develop alternate Caregiver plans for the care of your loved one in case of an unexpected illness or life event that affects your ability to continue providing care.
- Consider how you will support your friend or relative during a time of crisis, such as a natural disaster. The **Federal Emergency Management Agency (FEMA)** offers toolkits to help families plan for disability- and age-friendly evacuations.

CAREGIVER’S CHECKLIST

To summarize, these key tips and resources will help you along on your caregiving journey:

- ☐ Use a shared online calendar with the other people who provide care to your friend or loved one to stay on top of appointments.
- ☐ Establish routines for spending time with and checking in on your friend or relative outside of caregiving.
- ☐ Reach out to community services such as **Meals on Wheels** or **Area Agencies on Aging**.
- ☐ Make regular time for other family and friends by phone or in person.
- ☐ Ask other Caregivers, doctors, and medical providers about new technologies, like apps, that can make caregiving tasks easier.
- ☐ Discuss end-of-life care options (hospice vs palliative care) with the care recipient and other family members.
- ☐ Develop alternative care plans in case of an unforeseen event.

Achieving Acceptance

You've made plans. You've prepared for the expected and unexpected and realized that events will happen whether you want them to or not. Now, it's time to accept that you're doing all that you can, and to avoid judging yourself harshly for what might have been.

If you feel that you have experience to share, you may want to consider becoming an advocate and helping others who are confronting many of the issues you have already dealt with.

”

ADVICE
FROM THOSE
WHO KNOW

“It’s important to allow yourself to have thoughts (good or bad) and not judge those thoughts or yourself for having them. This will help you to accept things the way they are. Often times, too much thinking and overanalyzing become harmful to our mental health because we get caught up in trying to understand what the thoughts mean and what to do about them.”



EXERCISE:

Watching Leaves on the Stream

Instructions: The goal of this exercise is to learn how to accept your thoughts and feelings for what they are, which will help you build emotional strength.

- In your mind, picture a serene stream somewhere deep in the woods. Imagine that leaves have fallen from the trees into the stream, flowing along the surface of the water smoothly and uninterrupted.
- Pretend your thoughts act like the leaves on the stream. Whatever pops into your mind just calmly flows by. As you watch your thoughts float down the stream, try not to pass judgment or spend time getting caught up in them.
- The idea is to watch each thought flow by, accept it for what it is, and move onto the next thought.
- Use a stopwatch and do the exercise for 3 minutes. If possible, go somewhere quiet where you won't be interrupted!







Advice for Parents & Spouses

“The best thing to hold
onto in life is each other.”

.....

AUDREY HEPBURN

Stage 5 Collapse

Stage 6 Acceptance

Parents & Spouses

Important Resources

Introduction

Stage 1 Confusion

Stage 2 Realization

Stage 3 Frustration

Stage 4 Acknowledgment

PARENT & SPOUSE CAREGIVERS

Caregiving for your child or spouse presents its own set of challenges in these most intimate relationships. You may face disappointment (in the fact that the illness doesn’t align with your expectations for your family) and an overwhelming desire to nurture and protect him or her.

You may also feel guilt or shame about his or her condition or because of frustrations related to caregiving.

You may even feel loss or grief about what your relationship “should have been” before your loved one needed care.

The tips on the following pages can help you restore balance in both of your lives as you continue on this journey together.

IF YOU'RE CARING FOR YOUR: CHILD

- Reduce anxiety during the workday/school day by coming up with routines for checking in. Schedule a time for your child to call or text, or assign a specific ringtone to differentiate caregiving calls.
- Set up dates with other children or family members to give your child time and attention away from the illness. Also set up dates with your child separate from medical appointments to ensure quality time outside of the condition.
- Inform your child’s whole “ecosystem” (teachers, neighbors, parents of friends, etc) of his or her condition and how to best react in emergency situations. Be mindful of talking about it in a way that preserves dignity and maintains his or her self-image—thus promoting growth and acceptance. Highlight positive aspects of his or her abilities as well.
- The **Children’s Health Insurance Program (CHIP)** is a federal program that requires states to provide health insurance to children from families below certain income levels. Your state Medicaid agency can provide more information about this program, or you can get more information online.

To learn more, visit: <https://www.insurekidsnow.gov>
- If you are planning for your child’s future, consider **ABLE Accounts**, which create a special needs trust. Learn more about **ABLE Accounts**, tax-advantaged savings accounts for people with disabilities and their families, at: <http://www.ablenrc.org/about/what-are-able-accounts>

When communicating with your child:

1. Be honest, but age-appropriate. Be truthful in discussing your child’s illness, but use discretion in deciding how much to tell. Take into account your child’s age and development, and give an optimistic outlook in a way that’s still honest.
2. Use simple concepts and terms to describe the illness in a way your child will understand. Consult with a doctor or nurse if you’re unsure how to best do this.
3. When appropriate, use humor to lighten and soften the situation. Well-intentioned jokes can be used to make the situation less scary and will allow the circumstances to feel more normal.
4. Be careful not to suffocate your child with nonstop questions about how he or she is feeling, which could make your child feel like the disease is all there is to him or her.

- Stay up-to-date and file away all of your child's medical records from birth through adulthood. When your child becomes independent and in control of his or her own health care, this information will enable him or her to make informed and educated health decisions.
- Try to involve your other children in the treatment process when possible. This may help make the situation seem less frightening and more understandable for siblings.

To learn more, visit: www.kidshealth.org/parent/system/ill/caregivers.html

- Get involved in a carpooling routine (to school and after-school activities) with the parents of your children's friends. This will help lighten your load and make more time for both yourself and caring for your child.
- Encourage your child to participate in different social events with children of the same age. Some nonprofits even host summer camps designed for kids with disabilities.
- As your loved one reaches adolescence, it is important to create an intermediary step between constant monitoring and giving full control over health management to your child. Work with your loved one and his or her doctor to grant a "learner's permit" first, and then begin working toward the full-fledged "license." Allowing your child to earn independence gradually will help ensure he or she will follow the health plan, including his or her medication regimen, properly and without stress.

To learn more, visit: <http://www.apa.org/monitor/2011/03/ill-children.aspx>

IF YOU'RE CARING FOR YOUR:

SPOUSE

- The **Well Spouse Association** is a national organization that offers resources and guidance specific to Caregivers caring for a spouse. You can also search for spouse-specific local support groups, or utilize phone support groups and message boards to connect with others.

To find out more, visit: <http://www.wellspouse.org>.

- Set aside designated time for nonmedical conversations and activities to help maintain balance in the relationship. Use this time to talk about other family members, interests, world events, and fun memories, or to engage in hobbies and entertainment.

To learn more, visit: <https://www.aarp.org/home-family/caregiving/info-2014/caregiving-spouses-marriage-stress-jacobs.html>

ALLOW YOURSELF TO...

Arrange for an overnight break (or time off) from your loved one to catch up on sleep, and give you both personal space and room to breathe.

- Reach out to other family members, friends, or professional aides to help lighten the caregiving load. Just because you're married doesn't mean you're the only one who can help. Leaning on others for tasks that are especially taxing can prevent burnout and resentment. If financially feasible, hire an aide to handle nursing duties so that you can concentrate on being a partner to your spouse and fulfill other roles in your life, such as being a parent or employee.

To learn more, visit: <https://www.caregivers.com/caregiving/caregiver-to-your-spouse>

- While you may feel more comfortable keeping your marriage private, it is important to find at least one person you can confide in about caregiving. Reach out to a friend, religious leader, or someone you know who has shared a similar experience and use that person as a confidant.

To learn more, visit: <https://www.caregiving.com/2013/11/10-tips-for-spousal-family-caregivers>

- Because spousal caregiving over time can create a more imbalanced relationship, it is important to remind your spouse that he or she can give back to you by expressing heartfelt gratitude, love, and affection.
- Between you and your spouse, try to treat the condition like a third party in your relationship—something that you can both be mad at. Speaking to each other as if you’re upset with something else (the illness) rather than with one another can prevent conflict and strengthen your marriage.

- Writing letters to each other may make it easier to express thoughts about the relationship in a way that feels safe. It also may make it easier to communicate about difficult issues and provide an outlet for frustrations. You may choose to actually exchange letters, or to just use them as a way to clear up thoughts before face-to-face conversations.
- One of the most difficult adjustments to the relationship may be a loss of physical intimacy between you and your spouse. It's important to openly discuss this with your loved one. Try to strike a balance between expressing your own needs and keeping your partner's perspective in mind. For additional help, consider reaching out to a licensed therapist specializing in marriage or couples counseling.

To find a professional in your area, visit:
<https://www.aasect.org/referral-directory>

TALKING ABOUT DIFFICULT TOPICS

Difficult topics often make for difficult conversations, and many Caregivers struggle with communication with their loved one and other friends or family. Yet, effective communication is absolutely essential to the caregiving journey. Below is a list of key tips and tricks for communicating successfully with those around you. Refer back to these whenever you need a little help.

1. SPEAK FROM THE “I” AND STICK TO FEELINGS

Frame your statements in terms of what you feel or think, rather than focusing on the actions of others.
“I feel _____” or “I believe _____” instead of “You did _____.”

2. AVOID “ALWAYS” AND “NEVER”

Be specific when talking about a problem.

3. TIMING IS EVERYTHING

Pick the right time to have a conversation. Don’t introduce the subject when the moment is already tense.

4. MAINTAIN A HOPEFUL TONE

Keeping an optimistic tone throughout the conversation will help prevent it from spiraling to a negative place. You'll also likely find that a hopeful tone is reflected back at you.

5. TAKE ON THE OTHER PERSON'S PERSPECTIVE

Most importantly, put yourself in the other person's shoes. It's often helpful to verbalize that you're doing so. *"I understand that you _____ and that must be really hard. The way I feel about it is _____."*

6. EMPATHIZE, DON'T SYMPATHIZE

Try to feel what your loved one is feeling (empathy), instead of just feeling bad for him or her (sympathy). For instance, *"It's really hard to feel this sick"* can be more meaningful than *"Sorry you're feeling so sick."*

7. COMPROMISE IS KEY

Think about solutions before having the conversation, and be open to compromise during the conversation.





Important Resources

“Our life is what
our thoughts make it.”

.....

MARCUS AURELIUS

IMPORTANT RESOURCES

In addition to awareness, preparedness is key to the “Steady State” of caregiving. The following pages offer a list of resources along with helpful tools.

These important resources are provided for your reference only. Many of the organizations included in this section are unaffiliated with Novartis Pharmaceuticals Corporation. We are not responsible for the content of these organizations’ websites and/or the resources they provide.

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Stage 5 Collapse

Stage 6 Acceptance

Parents & Spouses

Important Resources

Introduction

Stage 1 Confusion

Stage 2 Realization

Stage 3 Frustration

Stage 4 Acknowledgment

Questions to Ask the Doctor

Often we can feel overwhelmed when visiting the doctor with our loved one, making it easy to forget to ask the important questions. Consider taking this list of questions with you to the next appointment. Use it during your conversation with the doctor and/or office staff, or scan it before leaving the appointment to make sure you haven't forgotten anything.

SYMPTOMS

- My loved one is experiencing the following symptoms. What could be causing them? Are they serious?

DIAGNOSIS

- What condition(s) does my loved one have?
- How is the condition diagnosed?
- What are the causes of this condition?
- What treatment options are available?
- What is the most effective treatment?
- What is likely to happen with and without treatment?
- Are there common complications associated with this condition?

MEDICATIONS

- What is/are the name(s) of the medication(s) you are prescribing?
- What are their benefits?
- What are the risks and side effects of taking the medication?
- Are there any safety precautions I should be aware of for the medication?
- How often and for how long should my loved one take this medication?
- What foods, other medicines, and activities should be avoided while taking this medication?
- Could this medication interact with any other medications?

Questions to Ask the Doctor (continued)

TESTS

- Are tests necessary?
- What will they show?
- Is there any preparation that is needed?
- When will we get the test results?
- What do the test results mean?

DIET AND EXERCISE

- Are there any dietary changes necessary?
- Do you recommend any additional vitamins or supplements?
- How often should he or she exercise?
- What types of exercises are safe?

OTHER LIFESTYLE

- Are the current living arrangements appropriate given the condition(s)?
- Are there any assistive devices or options I should consider?
- Should I make any modifications to my home?
- Is it okay to travel?

WRITTEN INSTRUCTIONS

- Do you have any written instructions that we can take home?

COSTS

- What costs can we expect?
- Will insurance cover this surgery/ test/treatment?
- What can we do to reduce costs?

SURGERIES

- Is surgery necessary?
- Are there alternatives to surgery?
- How is the surgery performed?
- Where will the surgery be performed?
- What risks are associated with this operation?
- What is the average recovery time?

HOSPITALIZATIONS

- How long will the person I’m caring for be in the hospital?
- Is there a patient advocate or social worker?
- What restrictions are on the patient while at the hospital? Any dietary or physical limitations?

FOLLOW-UP CARE

- Is a follow-up visit necessary?
- If so, when should we follow up?
- Do you recommend we see other providers (specialists, nutritionists, physical therapists, etc)?

Tracking Important Papers

Patient Name: _____

Social Security Number: _____

Address: _____

Date Prepared: _____

Copies Given To: _____

IMPORTANT NAMES, ADDRESSES, AND PHONE NUMBERS

Emergency Contact: _____

Doctor(s): _____

Clergy: _____

Attorney: _____

Accountant: _____

Insurance Agent/Policy Number(s): _____

Other Contacts: _____

Tracking Important Papers (continued)

ITEM	LOCATION
Loved one’s will (original)	
Loved one’s power of attorney—health care	
Loved one’s power of attorney—finance	
Spouse’s/partner’s will (original, if applicable)	
Combination/key to safe	
Trust agreement	
Life insurance policy	
Health insurance policy	
Homeowner’s policy	
Car insurance policy	
Employment contracts	
Partnership agreements	
List of checking, savings accounts	
List of credit cards	
Retirement papers	
Deferred compensation; IRA	
Funeral arrangements	
Titles and deeds	
Notes (mortgages)	
List of stored and loaned items	
Auto ownership records	
Birth certificate	
Military/veterans papers	
Marriage certificate	
Children’s birth certificates	
Divorce/separation records	
Passwords	
Other:	

Health Care Contact Information

Patient Name: _____

Diagnosis: _____

HEALTH CARE PROFESSIONALS

Primary Doctor: _____

Phone: _____ Affiliated Hospital: _____

Specialist: _____

Phone: _____ Affiliated Hospital: _____

Nurse: _____

Phone: _____

Social Worker: _____

Phone: _____

Home Care Attendant: _____

Phone: _____

Pharmacist: _____

Phone: _____

Other: _____

Phone: _____

Support Team Information

Consider family members as well as friends, neighbors, and colleagues who can offer support.

Name: _____

Relationship: _____

Phone: _____

Name: _____

Relationship: _____

Phone: _____

Name: _____

Relationship: _____

Phone: _____

Name: _____

Relationship: _____

Phone: _____

Name: _____

Relationship: _____

Phone: _____

Name: _____

Relationship: _____

Phone: _____

Name: _____

Relationship: _____

Phone: _____

Name: _____

Relationship: _____

Phone: _____

Medication List

Pharmacy Name: _____

Address: _____

Phone: _____

Insurance: _____

Policy Number: _____ Group Number: _____

Insurance Contact Info: _____

(Include special instructions for medications in Notes)

Name: _____

Dose: _____ Frequency: _____

Notes: _____

Name: _____

Dose: _____ Frequency: _____

Notes: _____

Name: _____

Dose: _____ Frequency: _____

Notes: _____

Medication List (continued)

Name: _____
Dose: _____ Frequency: _____
Notes: _____

Name: _____
Dose: _____ Frequency: _____
Notes: _____

Name: _____
Dose: _____ Frequency: _____
Notes: _____

Name: _____
Dose: _____ Frequency: _____
Notes: _____

Weekly Medication Schedule at a Glance

You may find it helpful to create a reference chart to keep track of your loved one’s medications. Simple visualization tools like this help us stay organized.

Here’s how it works: Below is an example of a completed chart for a person taking 4 medications with different dosing schedules. Simply write down the name of the medication in the appropriate box. We provided a blank chart on the following page that you can customize. Post it somewhere like the refrigerator door or by your medicine cabinet for quick reference. You may even want to create multiple copies and check off what’s been taken each week.

(EXAMPLE)

	MORNING	NOON	EVENING	BEDTIME
SUN	Medication 1	Medication 3	Medication 1	Medication 3
	Medication 2			
MON	Medication 4	Medication 4	Medication 1	Medication 4
			Medication 4	
TUE	Medication 1	Medication 3	Medication 1	Medication 3
	Medication 2			
WED	Medication 4	Medication 4	Medication 1	Medication 4
			Medication 4	
THU	Medication 1	Medication 3	Medication 1	Medication 3
	Medication 2			
FRI	Medication 4	Medication 4	Medication 1	Medication 4
			Medication 4	
SAT	Medication 1	Medication 3	Medication 1	Medication 3
	Medication 2			

Weekly Medication Schedule at a Glance (continued)

	MORNING	NOON	EVENING	BEDTIME
SUN				
MON				
TUE				
WED				
THU				
FRI				
SAT				

Insurance Company Call Log

Instructions: Record the date and time of your call below, as well as the name, title, and extension of the agent, for future reference.

Insurance Company Name:

Date: _____ Time: _____

Agent Name: _____

Notes: _____

Date: _____ Time: _____

Agent Name: _____

Notes: _____

Date: _____ Time: _____

Agent Name: _____

Notes: _____

Insurance Company Call Log (continued)

Date: _____ Time: _____

Agent Name: _____

Notes: _____

Date: _____ Time: _____

Agent Name: _____

Notes: _____

Date: _____ Time: _____

Agent Name: _____

Notes: _____

Date: _____ Time: _____

Agent Name: _____

Notes: _____

Resources for Caregivers

AIDS	
Centers for Disease Control and Prevention	www.cdc.gov 800.CDC.INFO (232.4636)
ALS	
ALS Association	www.alsa.org 800.782.4747
ALZHEIMER'S DISEASE	
Alzheimer's Association	www.alz.org 800.272.3900
Alzheimer's Foundation of America	www.alzfdn.org 866.232.8484
CANCER	
American Cancer Society	www.cancer.org 800.227.2345 (available 24/7)
CancerCare	www.cancercare.org 800.813.4673
Cancer.net	www.cancer.net 888.651.3038
CYSTIC FIBROSIS	
Cystic Fibrosis Foundation	www.cff.org 800.FIGHT.CF (344.4823)
DIABETES	
American Diabetes Association	www.diabetes.org 800.342.2383
FEDERAL AGENCIES AND PROGRAMS	
Administration for Community Living	www.acl.gov www.longtermcare.acl.gov
Centers for Disease Control and Prevention (CDC)—Tips for Caregivers of People with Disabilities	www.cdc.gov/ncbddd/disabilityandhealth/family.html
Medicare	www.medicare.gov
Medicaid	www.medicaid.gov
US Department of Veterans Affairs—Caregiver Support Program	www.caregiver.va.gov 855.260.3274

Resources for Caregivers (continued)

DISABILITIES	
National Alliance for Caregiving	www.caregiving.org 301.718.8444
HEART DISEASE	
American Heart Association	www.heart.org 800.242.8721
LUNG DISEASE	
American Lung Association	www.lung.org 800.548.8252
MULTIPLE SCLEROSIS	
National Multiple Sclerosis Society	www.nationalmssociety.org 800.344.4867
OLDER ADULTS	
National Association of Area Agencies on Aging (n4a)	www.n4a.org 202.872.0888
National Council on Aging – Benefits Checkup	www.benefitscheckup.org
National Aging and Disability Transportation Center	www.nadtc.org 202.872.0888
Eldercare Locator	www.eldercare.gov 800.677.1116
PARKINSON'S DISEASE	
Parkinson's Foundation	www.parkinson.org 800.327.4545
STROKE	
American Stroke Association	www.strokeassociation.org 888.478.7653
ADDITIONAL SUPPORT	
American Association of Retired Persons (AARP)	www.aarp.org
Caregiver Action Network	www.caregiveraction.org
Family Caregiver Alliance – Family Care Navigator	www.caregiver.org/family-care-navigator
Mended Hearts	www.mendedhearts.org

Caregiver's Checklist

Don't forget to keep these tips and resources close as you continue on your caregiving journey.

Stage 1: Confusion

- ☐ Identify a core care team of health care professionals (*doctors, pharmacist, social worker*) and personal supporters (*family, friends, neighbors*). Keep their contact information handy.
- ☐ Complete a Health Care Proxy form to obtain full communication rights.
- ☐ Find out if your state has enacted the CARE Act, which guarantees Caregivers certain rights upon hospital discharge.
- ☐ Contact disease-specific foundations for educational materials.
- ☐ Ask the doctor, nurse, or pharmacist questions you may have about medication routines, side effects, etc.

Stage 2: Realization

- ☐ Contact your loved one's insurance company to find out about home health aide coverage and options. Refer to **A Caregiver's Bill of Rights** when you feel uncertain.
- ☐ Contact an attorney for advice regarding legal affairs, including a living will, power of attorney, and last will and testament.
- ☐ Contact the medication manufacturer to inquire about financial assistance programs.
- ☐ Contact your local Area Agency on Aging for information on community resources.
- ☐ Find out from your doctor or the American Red Cross if there are any Caregiver training programs offered in your area.
- ☐ Try medication-management techniques such as pill organizers, electronic reminders, alarms, or the Medication Checklist to see what works best for you.

Stage 3: Frustration

- ☐ Rely on your local pharmacist and your medical office's nursing line for questions regarding changes in symptoms or difficulties adhering to medication routines.
- ☐ Keep all medical documents in a binder, complete with emergency contacts and space to log doctor visits.
- ☐ Find relaxation techniques that work best for you, such as taking a brief walk or journaling.
- ☐ Keep copies of the medication list easily accessible and on hand at all times.
- ☐ Speak to your workplace's HR department about eligibility for Family and Medical Leave.
- ☐ Pack an overnight bag for you and the care recipient for emergencies that require unexpected hospital stay.

Caregiver's Checklist (continued)



Stage 4: Acknowledgment

- ☐ Reach out to administrators in hospitals or assisted living facilities for a network of support services and medical supply companies.
- ☐ Determine the existence and location of all insurance policies, not just medical ones.
- ☐ Speak with your care team or an occupational therapist about modifying your loved one's home to be safe and secure.
- ☐ Enroll in an auto-refill program through the pharmacy to stay on top of refills.
- ☐ Talk with your loved one and other Caregivers about long-term care plans.
- ☐ Consolidate medication prescriptions at a single pharmacy.



Stage 5: Collapse

- ☐ Join a local Caregiver support group or participate in an online support group.
- ☐ Make your health a priority—join a gym or a fitness class, or search online for nutritious recipes.
- ☐ Explore alternative therapies such as art or music therapy to rejuvenate energy and mood.
- ☐ Consider consulting a trained professional if you feel like you need an outlet outside of your friends and family.
- ☐ Schedule regular medical care for yourself.
- ☐ Contact local houses of worship for assistance or support.
- ☐ Make personal time a priority by scheduling time for yourself and opting for in-home care/day-care services to help give you some extra time for a break.



Stage 6: Acceptance

- ☐ Use a shared online calendar with the other people who provide care to your loved one to stay on top of appointments.
- ☐ Establish routines for spending time with and checking in on your loved one outside of caregiving responsibilities.
- ☐ Make regular time for other family and friends, by phone or in person.
- ☐ Ask other Caregivers and doctors about new technologies, such as apps, that can make caregiving tasks easier.
- ☐ Discuss end-of-life care options (hospice vs palliative care) with your loved one and other family members.
- ☐ Develop alternative care plans in case of an unforeseen event.
- ☐ Reach out to community services such as Meals on Wheels or your Area Agency on Aging.

Notes

THIS IS NOT THE END.

Every day is a new beginning; a new day on your caregiving journey. And while each one may present different challenges—some surprises, some frustrations, some relief—it is important to remain focused on the overall goal: knowing what to expect emotionally and, in part, knowing how and where to get the help you need when you need it.

That is what we call **“Achieving the Steady State.”**

Acknowledgments

Creating this guide took the help of:



The result:

**A resource of knowledge
and understanding.**

*Many thanks to everyone who helped with this project
for their passion and compassion.*

“You gain strength,
courage, and confidence
by every experience
in which you really stop
to look fear in the face.

*You must do the thing
you think you cannot do.”*

.....

ELEANOR ROOSEVELT

