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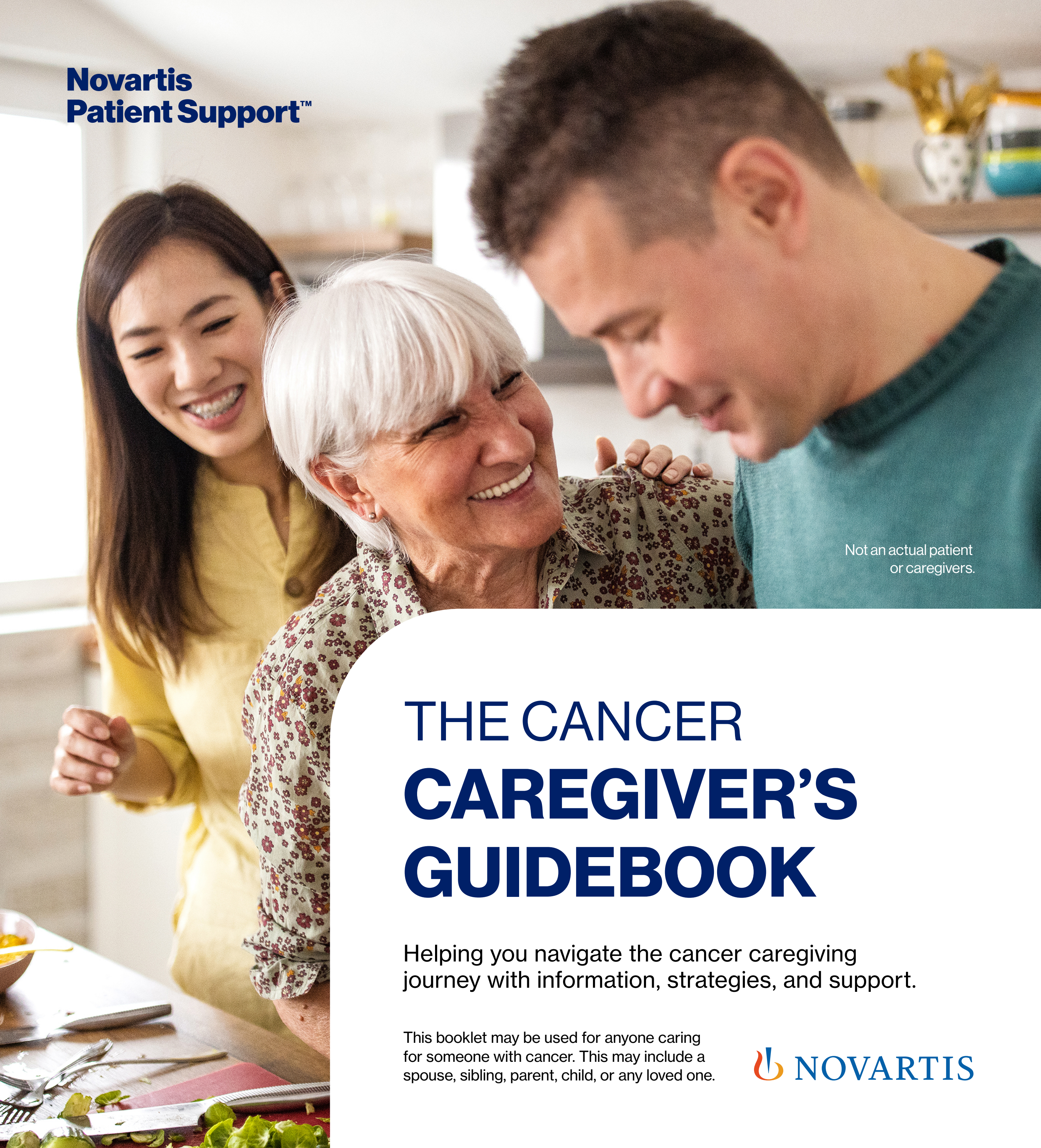

THE CANCER
CAREGIVER'S GUIDEBOOK

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

This booklet may be used for anyone caring for someone with cancer. This may include a spouse, sibling, parent, child, or any loved one.

NOVARTIS

“**Where there is love there is life.**”

MAHATMA GANDHI

It happens in an instant

Your loved one received the diagnosis. It's cancer. And just like that, both of your lives are forever changed. Your loved one now begins the hardest journey of his or her life.

But your cancer journey begins, too. In what seems like overnight, you have become the emotional supporter and physical caretaker. You may also be the decision maker, the researcher, or bill payer. You might even have to 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.

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A Guidebook **to support you**

We believe strongly that **caregiving is a lifestyle,** and we need and deserve to live it better.

You are your loved one's advocate.

You, more than anyone, know them best. 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.

Not an actual patient or caregiver.

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

This guidebook will give you:

- ☑ Information on what to expect along the way
- ☑ Helpful strategies to cope with challenges
- ☑ Tools and tips to successfully manage the day-to-day

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 cancer caregiving journey a smoother one.

You’re not alone

We are a nation of 53 million family Caregivers.[1] On average, we’re spending 24 hours a week caring for others.[1]

53 million American adults serve as Caregivers[1]

39%[1*] men

61%[1*] women

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

Only **32%** of Caregivers have reported using the Internet to search for services, aides, facilities, or other help to support their loved one.[1] (This is where this guidebook—and other useful tools and resources—come in.)

89%

of Caregivers care for a relative[1]

Caregiver ages range across the board[1]:

24% 18–34

23% 35–49

35% 50–64

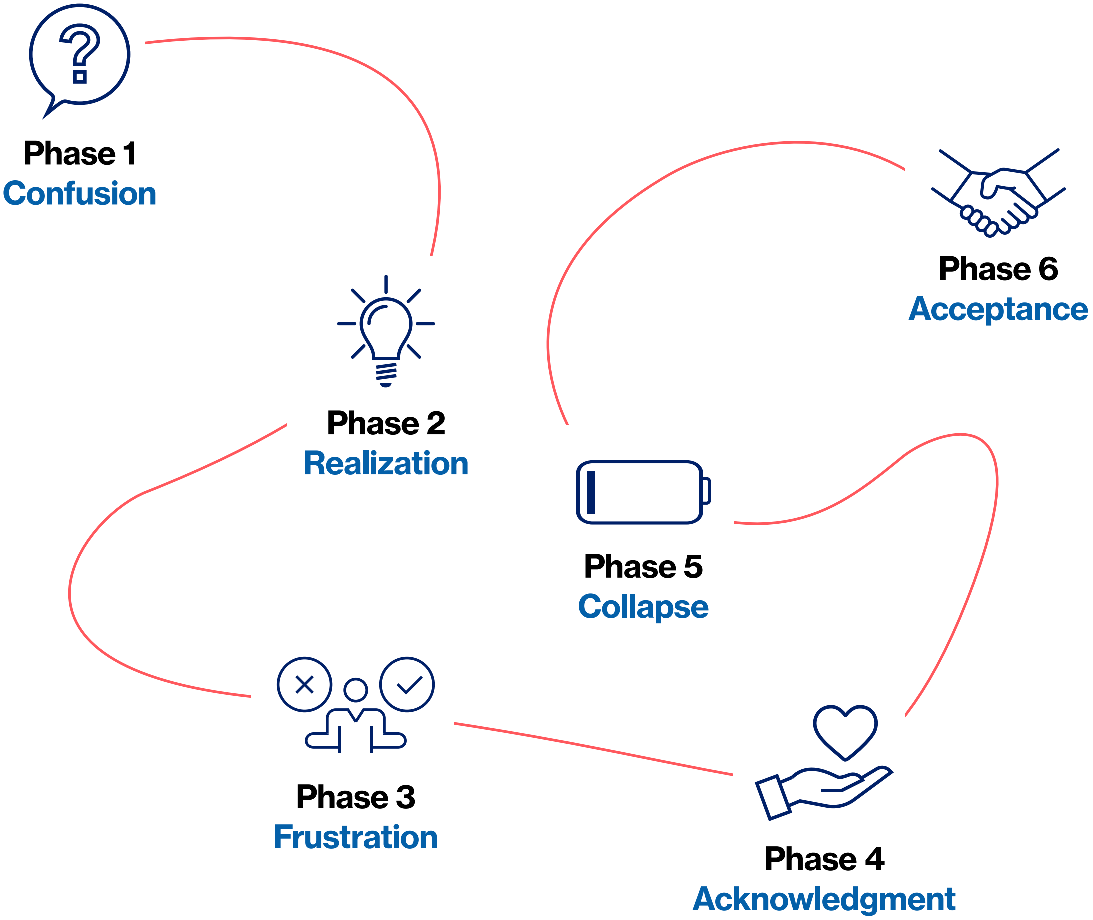
19% 65+

References: 1. AARP and National Alliance for Caregiving. Caregiving in the United States 2020. https://www.aarp.org/content/dam/aarp/ppi/2020/05/full-report-caregiving-in-the-united-states.doi.10.26419-2Fppi.00103.001.pdf. Published May 2020. Accessed September 14, 2021.

The cancer Caregiver journey

Creating a better lifestyle for Caregivers is an extraordinary challenge. The 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 phases 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 phases 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 it a more level journey, so they can be more even-keeled in the most stressful of times. Rather than fighting the highs and lows, it's about expecting them and preparing for them. It's about controlling them through emotional awareness.

Steady-State Caregiving is a philosophy and a system designed to help Caregivers like 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.

Not an actual
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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."

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Phase 1

Confusion

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How you’re feeling

Information overload

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

Hurried handoffs

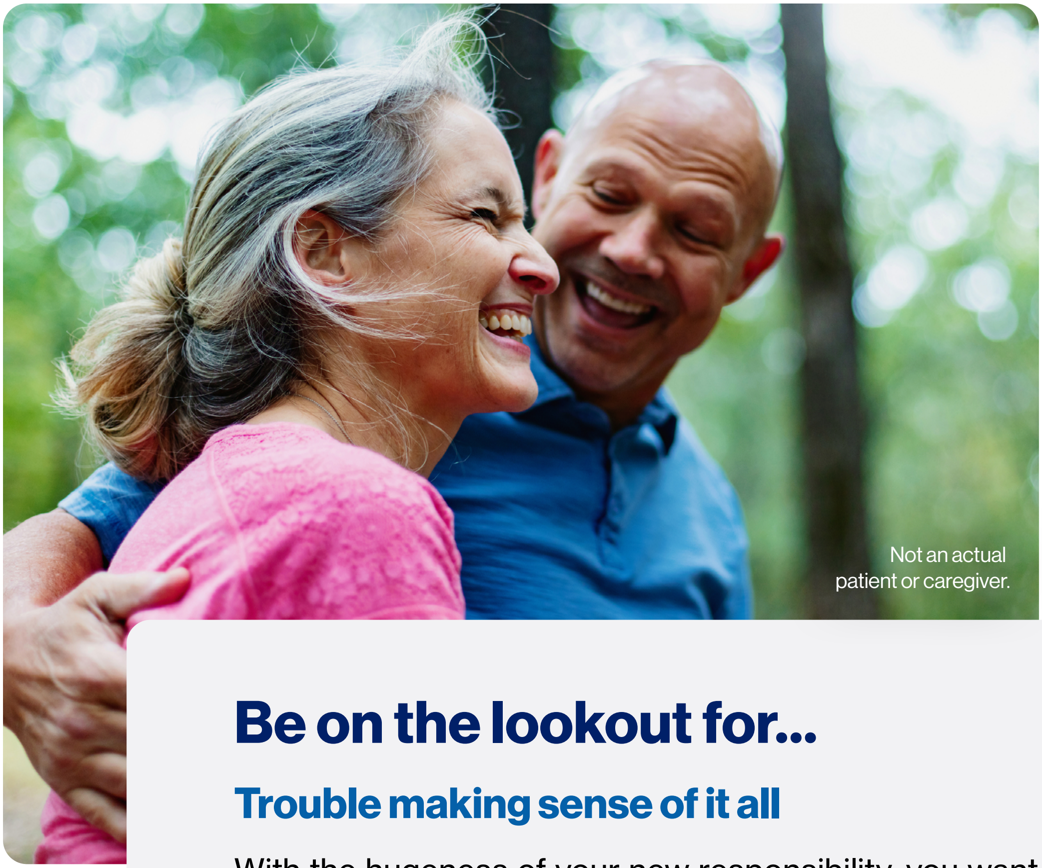
In the chaos of it all, you may also feel like the doctors and nurses didn’t take the time to properly loop you in on arrangements and treatment routines.

Unspoken arrangements

In some cases, you may even experience remorse and regret over never having discussed the possibility of your loved one needing care, and what that would mean for your relationship.

A Caregiver’s Journey

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



Not an actual patient or caregiver.

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 oncology 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."

Tip 1: Build your cancer 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

☐ Primary Care Doctor
☐ Nurses
☐ Psychologist/Social Worker
☐ Oncologist
☐ Home Care Attendant
☐ Pharmacist
☐ Other ____________________

Personal Support Network

☐ Family Member
☐ Additional Family Members *(They're that important)*
☐ Friends
☐ Colleagues
☐ Neighbors
☐ Other ____________________

Once you've identified your care team, record their contact information on **pages 110 and 111** and keep it close by.

Not an actual patient or healthcare provider.

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 cancer caregiver.

Find out what's expected of you in terms of monitoring symptoms, helping with medications, emotional support, etc. Prepare a checklist of your questions. We've started a list on **page 104.**

> "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...

Your loved one 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 them to not feel cut out of the process**
  Assure your loved one that he/she 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 in-home help as something that will help you as Caregiver**
  For example, someone to help do grocery shopping for you.

Tip 2: Know your rights

- Consider asking your loved one to complete a **Health Insurance Portability and Accountability Act (HIPAA) release form** authorizing you to have access to his/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.hipaajournal.com/hipaa-release-form, or ask your medical provider for more information.

Links to: https://www.hipaajournal.com/hipaa-release-form/

- Consider asking your loved one to complete a **health care proxy** form so that you can make medical decisions on behalf of your loved one, if necessary. Please search online for your state's version of this form.

- 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 loved ones are admitted to a hospital and after discharge 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: https://www.aarp.org/politics-society/advocacy/caregiving-advocacy/info-2014/aarp-creates-model-state-bill.html

Links to: https://www.aarp.org/politics-society/advocacy/caregiving-advocacy/info-2014/aarp-creates-model-state-bill.html

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Tip 3: Seek out community resources

- Special support services are available to **veterans** and their Caregivers. If applicable, find out if your loved one qualifies for some of these services.

> **The National Alliance for Caregiving** provides links to numerous resources at: https://www.caregiver.org/resource/caregiving-and-veterans/

Links to: https://www.caregiver.org/resource/caregiving-and-veterans/

- Today, several organizations support patients based on specific types of cancer.

> The Cancer Support Community (CSC) provides information and support for just about every cancer type at: www.cancersupportcommunity.org/learn-about-cancer-types

Links to: http://www.cancersupportcommunity.org/learn-about-cancer-types

See **pages 118-121** for a list of cancer foundations that can help.

> "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."

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78% of Caregivers manage multiple or complex medications for their loved ones[1]

Tip 4: Manage treatment

- 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 know if the drug is working or not working?
  - What are potential side effects?
  - How do I know if my loved one is experiencing a side effect?
  - Is this drug a brand name or generic?
  - What is the difference between a generic and brand-name medication that would be used to treat this type of cancer?
  - Is this medicine safe to take with the other drugs my loved one is currently taking?
  - Is there a way to minimize the number of medications or supplements?
- Chemotherapy, radiation, and other types of therapies require a more in-depth discussion. Use the questions on **pages 105 and 106** to begin that dialogue.
- Ask doctors or pharmacists for guidance on how to best organize and adhere to medications.

You can record medications starting on **page 112** to keep as a reference, especially when speaking with a member of your loved one's health care team.

Reference: 1. Goyer A. A caregiver's tips for managing medications; AARP Web site. http://blog.aarp.org/2012/10/10/amy-goyer-caregivers-medical-tasks/. Published October 10, 2012. Accessed November 11, 2016.

Caregiver’s checklist

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

☐ Identify a core care team of health care professionals (oncologist, pharmacist, psychologist, social worker) and personal supporters (family, friends, neighbors). Keep their contact information handy.

☐ Request that your loved one 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 cancer foundations for educational materials.

☐ Ask the primary care doctor, oncologist, nurse, or pharmacist questions you may have about medication routines, other therapy, side effects, and generic alternatives.

Caring for the Caregiver

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. And that often means reducing your feelings of distress and calming yourself down.

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, 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're confused will help you stay fueled up over the course of your loved one's disease. 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 1 or 2 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?

PEACEFUL MOMENTS 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 make it through.

Not an actual
patient or caregiver.

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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."

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Phase 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 and making

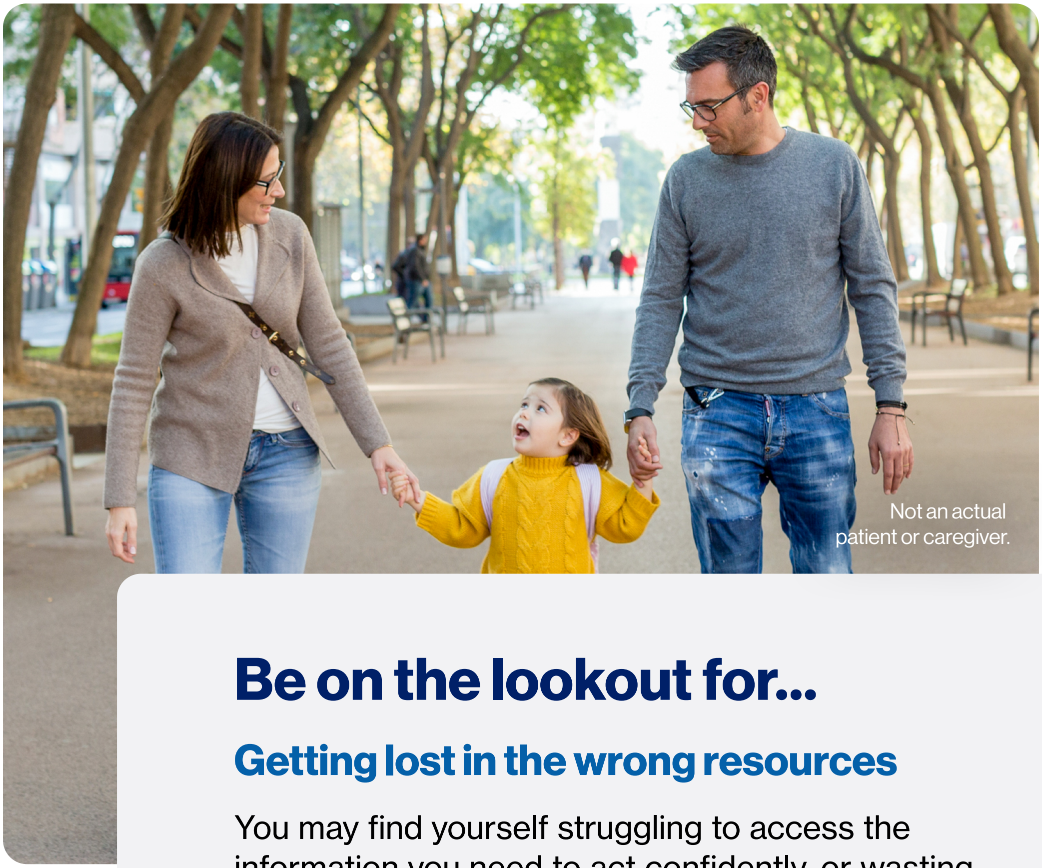
You're not the only one with a new role. The entire family often has a part to play, as medicine patroller, therapist, and more.

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 my loved one, who would?"



Not an actual patient or caregiver.

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 my loved one and for our relationship."

Tip 1: Build your cancer care team

- Call your loved one's insurance company to learn about coverage of home health care services (such as aides to help with routine hygiene). Keep a record of each call for future reference.

> See **pages 116 and 117** for a call log that you can use.

- Consider speaking with your employer about your caregiving situation. Looping them in early on can reduce stress later in the case of unforeseen emergencies or absences.

It's a family affair

Cancer caregiving doesn't only affect your life and that of your loved one. 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 (especially since cancer can be just as shocking a diagnosis for them as it was for you and your loved one). 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, like a family counselor, to help solve conflicts.

Tip 2: Know your rights

Refer to the following Caregiver 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.

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

Links to: https://www.aarpmedicareplans.com/medicare-education/medicare-parts-and-medigap-plans.html

> To learn more, visit: https://www.aarpmedicareplans.com/medicare-education/medicare-parts-and-medigap-plans.html

- 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: https://www.americanbar.org/groups/real_property_trust_estate

Links to: https://www.americanbar.org/groups/real_property_trust_estate

- 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 my loved one, but happy that I could help them in some way."

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Tips & tools Keep a list of the whereabouts of important documents, files, and accounts. The form on **pages 108 and 109** can help.

Tip 3: Find financial assistance

- Did you know that your loved one's medication manufacturer may offer financial assistance? Call the pharmaceutical company to inquire about financial support programs or copay 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 your loved one about expectations for your cancer Caregiver role. For instance, who will be responsible for items not covered by insurance? Take into account the costs of therapy, special dietary requirements, toiletries, home goods, transportation, and other day-to-day costs. Clearly defining these responsibilities early on 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 of your loved one's financial accounts. Determine together whether you should have access to his/her:
  - Checking account
  - Savings account
  - Other assets (stocks, bonds, etc)
  - Real estate and other property documentation
  - Safety deposit box/security box or home safe

Tip 4: Seek out community resources

- If you are caring for someone who is elderly, 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 elderly.)

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

Links to: https://www.usaging.org/

- Some organizations, like the **Caregiving Action Network**, offer Caregiver support programs.

> To learn more, visit: https://www.caregiveraction.org

Links to: https://www.caregiveraction.org/

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Tip 5: Manage treatment

- In some cases, people simply fail to take their medication because they can’t remember. Help yourself and your loved one with medication management that complies with the directions in which the medication should be taken. Check with your oncologist or pharmacist first, but some of these techniques may be appropriate:
  - A pillbox
  - Electronic reminders
  - Combining with a daily task, like 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 a habit around remembering to take medication
  - Keeping medication visible, perhaps out on a kitchen counter (if there are no small children in the home)
  - Enlisting a loved one’s help. Have your loved one take meds when you are on the phone or in person

Caregiver's checklist

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

- ☐ Contact your loved one's insurance company to find out about home health aide coverage and options.
- ☐ Refer to the **Caregiver 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 **Family Caregiver Council** if any Caregiver support programs are offered in your area.
- ☐ Try medication-management techniques to help you and your loved one stick with the routine, and use the Medication List (**pages 112 and 113**) to help stay on track.

Caring for the Caregiver

Achieving realization

During this phase, it can be easy to focus on the negative 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 the pain away 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 as they apply to the changes you've undergone since becoming a cancer Caregiver. Do any of your answers surprise you? Boxes may be typed within.

What has changed?

Example: Since having to become a Caregiver for my youngest child, I'm now only able to work part time.

What has 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 Mondays and Fridays to relieve some of the stress on me.

Not an actual
patient or caregiver.

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, their 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?"

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Phase 3

Frustration

How you’re feeling

Self-reflection

Here you may start to think more about what the role of a cancer Caregiver means, and you may often find yourself battling conflicting emotions about the impact of caregiving on your own life.

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 cancer caregiving 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 oncologist, the person being cared for, and the cancer 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 they were sick.”

Not an actual patient or caregiver.

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.”

Tip 1: Build your cancer 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 your loved one 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 your loved one's 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 your loved one'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 **112 and 113**

- 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.

Tip 2: Know your rights

- If you are caring for someone who is far away and elderly, consider installing a video monitoring system (with your loved one's permission, of course). These cameras can monitor your loved one's daily activities and provide you with a direct video feed onto your smartphone, tablet app, or the Web.

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

Links to: http://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.

> To learn more about the **Family and Medical Leave Act**, visit: https://www.dol.gov/agencies/whd/fmla

Links to: https://www.dol.gov/agencies/whd/fmla

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.”

Tip 4: Plan for the unexpected

- Keep a complete file of your loved one's medical history, medications, dosages, and emergency medical contacts on hand so you have quick access in times of urgent changes (see **pages 108–117**). 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 your loved one 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/oncologist immediately following discharge from the hospital to discuss any changes to your loved one's life.

- If the chemotherapy that your loved one is getting does not work, the doctor may or may not suggest a second-line therapy. Keep a list of questions with you and be prepared to talk about your preferences.
- There is a chance that your loved one's cancer may return after successful treatment, sending you both back to the emotional state felt during the initial diagnosis. This is called **Relapse**. Dealing with the emotional distress of a relapse is important. This may be a good time to consider counseling or joining a support group for you and your loved one.

> "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 cancer 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 your loved one’s medication list easily accessible and on hand at all times.
- ☐ Speak to your workplace’s HR department about eligibility for the Family and Medical Leave Act.
- ☐ Find relaxation techniques that work best for you, such as taking a brief walk or journaling.
- ☐ Keep all medical documents in a binder, complete with emergency contacts and space to log doctor visits.
- ☐ If you are a long-distance Caregiver, gather a list of the important contacts from your loved one’s neighborhood.
- ☐ Pack an overnight bag for your loved one and yourself for emergencies that may require an unexpected hospital stay.

Caring for the Caregiver

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.

ADVICE FROM THOSE WHO KNOW

> "We now know through scientific studies that when we put our thoughts into words by journaling, stress is reduced and our immune system is strengthened. Over time, the practice of taking 15-20 minutes out of your 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."

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

1	2	3	4	5	6	7	8	9	10

Feeling very calm *Feeling extremely upset*

After temperature

1	2	3	4	5	6	7	8	9	10

Feeling very calm *Feeling extremely upset*


Not an actual
patient or caregiver.

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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."

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Phase 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

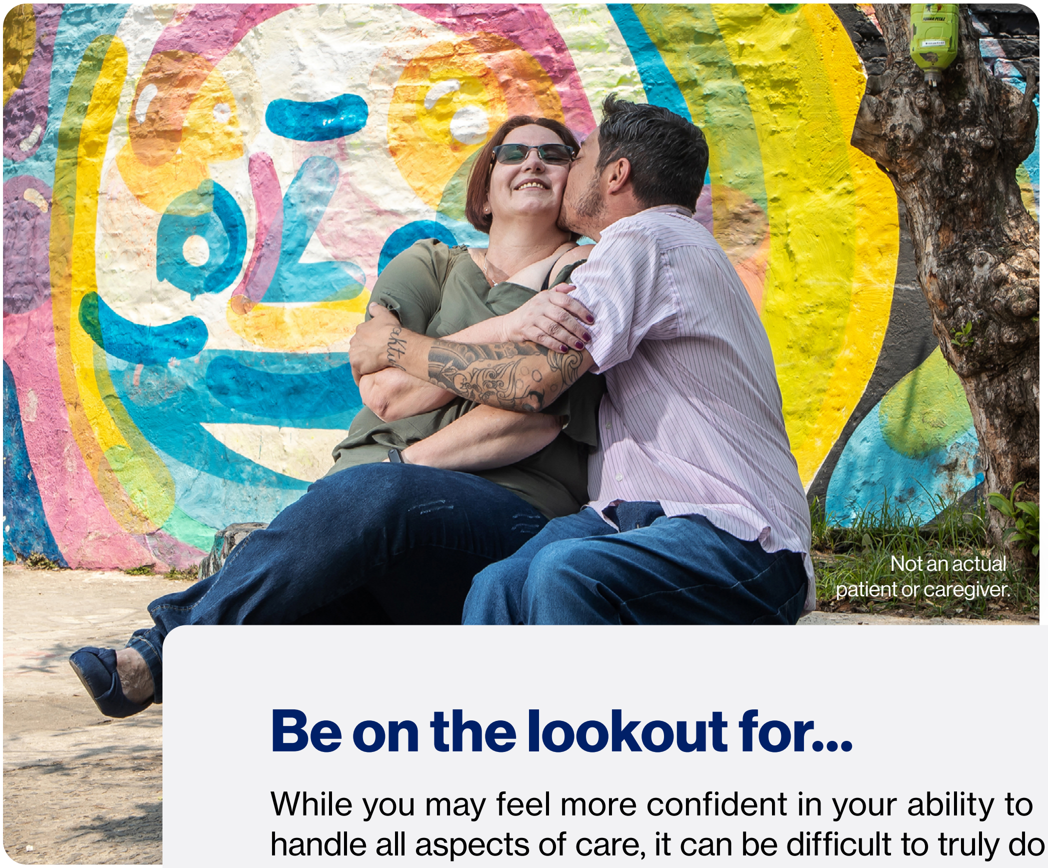
Some research has recognized the idea of “Caregiver Gain,” which is when you start to feel that your own well-being has improved as a result of your new role.

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.”



Not an actual patient or caregiver.

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're given.

> "My loved one depended on me and trusted me. I was the only one who understood their needs. But this made me feel like I was the only one who could really help them. It was lonely and sometimes scary, too."

Tip 1: Build your cancer care team

- Use every encounter with your loved one's oncologist and other providers as an opportunity to learn more about the disease.
- If your loved one is dealing with the side effects associated with chemotherapy, radiation, or similar treatments, ask your care team about other therapies that may help relieve some of his or her discomfort, such as acupuncture.
- 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.

- Speak with your care team about modifying your loved one’s home to be safe and secure. An occupational therapist can evaluate the challenges and shortcomings of your loved one’s 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 someone elderly who is in an assisted living facility far away, schedule conference calls with doctors, the assisted living facility team, or the nursing home staff so that several family members can participate in 1 conversation and get up-to-date information on your loved one’s health and progress.

Tip 2: Manage treatment

- If possible, use the same pharmacy to fill all of your loved one's prescriptions since this will help to ensure that a personal medication profile is created and maintained for his or her course of treatment.
- If instructed by the doctor or nurse, use a personalized treatment calendar that lists the dates and times that your loved one should take his or her oncology medication, and take this calendar with you to your medical appointments to show to your health care team.
- Have a designated, consistent, and safe area at your home to store his or her oncology medication.
- Let family members or any other Caregivers who will be assisting your loved one with treatment know about his or her therapy and provide them with the materials given to you by the doctor or nurse.

> "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."

Tip 3: Plan for the unexpected

- Have the conversation regarding long-term care with your loved one and core family members. 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 cancer Caregivers through entire conversations.

- Determine the existence and location of all insurance policies (medical, disability, house, car, long-term care, life insurance, and VA).

- Keep a visual record of medications and documents on your smartphone.

- Need help organizing meals for your loved one?

> Investigate how at: www.mealtrain.com

Links to: http://www.mealtrain.com/

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Caregiver's checklist

To summarize, these key tips and resources will help you along on your cancer 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 your loved one's home to be safe and secure.
- ☐ Consolidate medication prescriptions to 1 pharmacy.
- ☐ Enroll in an auto-refill program through the pharmacy to stay on top of refills.
- ☐ Talk to your loved one and other family members about long-term care plans.
- ☐ Determine the existence and location of all insurance policies, not just medical ones.

Caring for the Caregiver

Achieving acknowledgment

Now that you may be starting to come to terms with your role as cancer 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.

ADVICE FROM THOSE WHO KNOW

> "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."

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. ____________________

Not an actual
patient or caregiver.

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Collapse

A Caregiver's Journey

"I really believed I had everything in control. My loved one 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."

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Phase 5

Collapse

How you’re feeling

Putting yourself second

Sometimes you end up sacrificing your own health for that of your loved one. 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

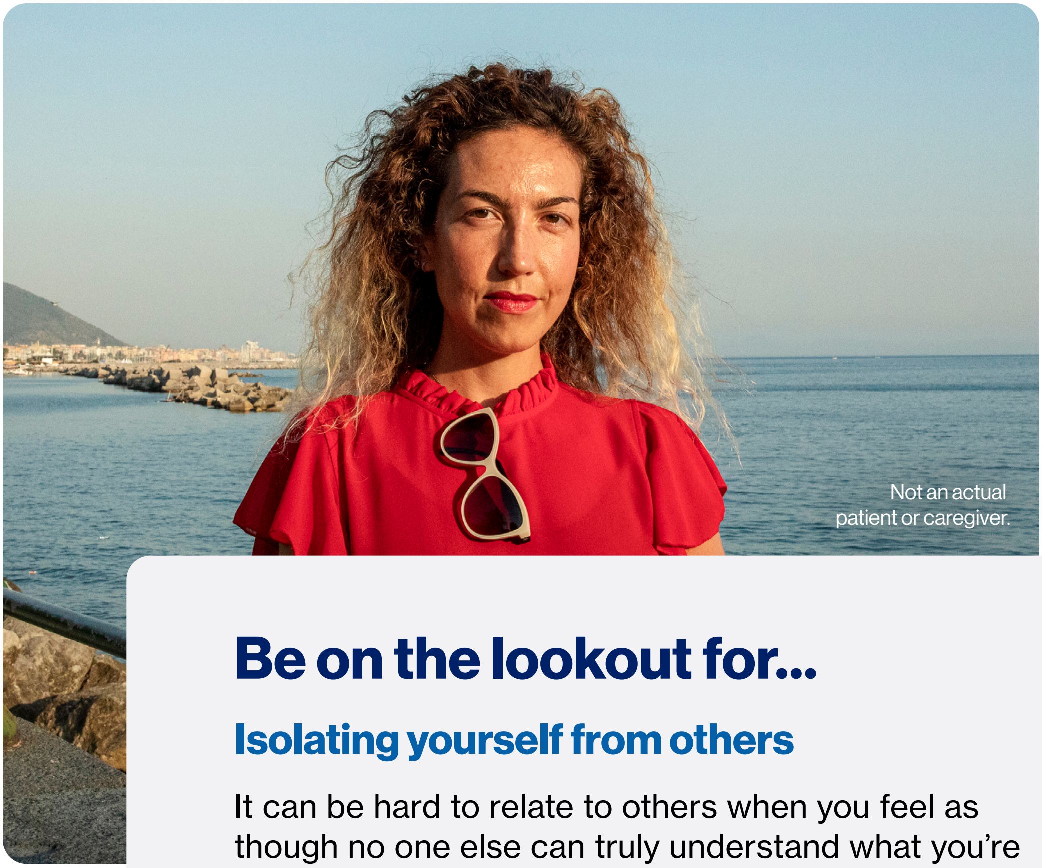
You may even be bottling up those “unthinkable” and “unacceptable” thoughts, preventing honest communication with others, which sometimes creates resentment.

One-sided caregiving

Caring for family is frequently placed above caring for oneself, making you a poor role model for practicing healthy behaviors, such as taking medication properly and exercising.

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.”



Not an actual patient or caregiver.

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 burden.

"I hit a breaking point. The lowest of lows. I was exhausted, broken, depressed and I questioned whether things would ever change or improve. My loved one's health was stable, but now I was the one suffering."

Tip 1: Build your cancer care team

- Join a local cancer 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 cancer foundations or your local hospital. You can search online to see which ones are available in your area.

- 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 cancer specific and can also be on Caregiver-focused websites or general social media platforms like Facebook.

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: www.caregiver.org/depression-and-caregiving

Links to: http://www.caregiver.org/depression-and-caregiving

- Be sure to schedule regular medical care for yourself and report any changes in your health to your doctor.

- Alternative therapies, such as art or music therapy, could also help you restore energy, improve mood, and help your body heal 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.

- Color can have a dramatic impact on mood for cancer patient 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 them, 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?”

Tip 3: Plan for the unexpected

- Contact local houses of worship (eg, churches, 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 child/adult day care 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: www.archrespite.org

Links to: http://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.

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Caregiver's checklist

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

- ☐ Join a local cancer 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 loved one can't be left alone.

Caring for the Caregiver

Coping with collapse

At this phase, 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 you have your loved one’s urgent needs 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 cancer 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.

Directly affects your love one?

Urgent?	Yes	No
Yes	**1.** Do Most important tasks. You have to do them now *(eg, call doctor about any new symptoms)*	**2.** Delegate Tasks that can be delegated to others *(eg, grocery shopping)*
No	**3.** Plan Tasks you must plan or they'll become urgent *(eg, pick up prescription refill)*	**4.** Nourish Things that I can do for me time *(eg, go on a jog, do IMPROVE exercises, journal)*


Not an
actual patient.

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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 my loved one wouldn't be getting better; their 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 them."

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Phase 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

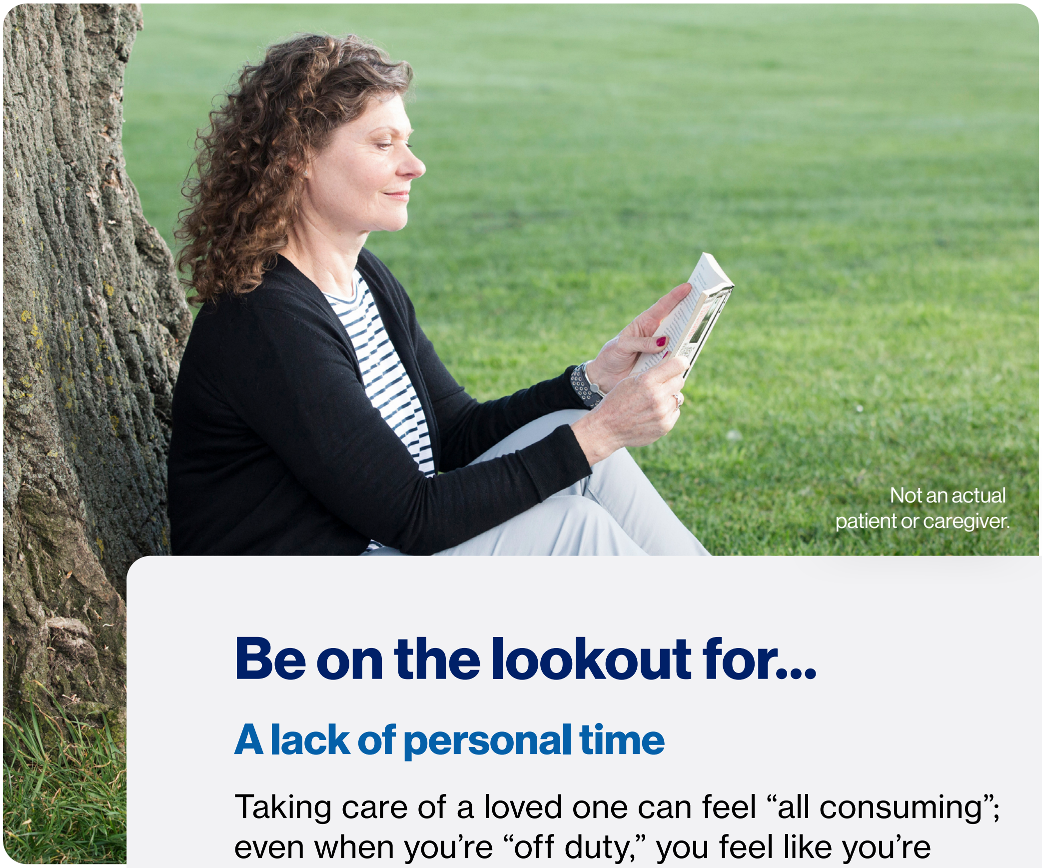
Many Caregivers express gratitude for the ability to connect online with other Caregivers. They use social media, forums, and other websites to share their journeys and read about the journeys of others.

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 they deserved—but not lose myself in the process.”



Not an actual patient or caregiver.

Be on the lookout for...

A lack of personal time

Taking care of a loved one 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?”

Tip 1: Build Your cancer 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 Android Market™ . 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.

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 cancer Caregiver role.

> “With this acceptance and all of the knowledge I’d acquired, I was able to move forward with a positive mind-set. 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.”

Tip 3: Seek out community resources

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

> To learn more about **Meals on Wheels**, visit:
> www.mealsonwheelsamerica.org

Links to: http://www.mealsonwheelsamerica.org/

Tip 4: Manage treatment

- Be open to new technologies that could help relieve some of your cancer caregiving duties, including mobile apps and products. For instance, wireless pillboxes or medication reminder apps could help keep your loved one adherent.

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Tip 5: Plan for the unexpected

- Know the difference between palliative care and hospice care. Both care types offer 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.

- Although a difficult subject to talk about, discussing end-of-life care with your loved one will ensure that you know his/her wishes if the time comes.

- Address your spiritual needs, as well as those of your loved one. Make sure you understand your loved one's end-of-life wishes regarding religious preferences and burial.

- Develop alternate cancer 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.

Caregiver's checklist

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

☐ Use a shared online calendar with the other people who provide care to your loved one to stay on top of appointments and therapies.

☐ Establish routines for spending time with and checking in on your loved one outside of caregiving responsibilities.

☐ Reach out to community services such as Meals on Wheels or local transportation offerings.

☐ Make regular time for other family and friends by phone or in person.

☐ Ask other Caregivers and doctors about new technologies, like apps, that can make cancer 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.

Caring for the Caregiver

Achieving acceptance

At this phase, 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 you have your loved one's urgent needs always top of mind.

But it's important in this moment to 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

"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. Oftentimes, 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!

Not an actual
patient or caregiver.

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Advice for parents & spouses

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

AUDREY HEPBURN

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Parent & Spouse **Caregivers**

Cancer 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 your loved one.

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

- Inform your child's whole "ecosystem" (teachers, neighbors, parents of friends, etc) of the disease and how to best react in emergency situations.

- The **Children's Health Insurance Program (CHIP)** is a federal program that requires states to provide health insurance to children from families with 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: www.insurekidsnow.gov

Links to: http://www.insurekidsnow.gov/

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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/she is feeling, which could make your child feel like the cancer is all there is to him/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: https://kidshealth.org/en/parents/serious-illness.html

Links to: https://kidshealth.org/en/parents/serious-illness.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.

- As your loved one reaches adolescence, it is important to create an intermediary step between helicopter monitoring and giving full control over medication 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 medication regimen properly and without stress.

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

Links to: http://www.apa.org/monitor/2011/03/ill-children.aspx

*Listing of an organization does not imply an endorsement by Novartis Pharmaceuticals Corporation. Links for external websites are independently operated and not managed by Novartis Pharmaceuticals Corporation. Novartis assumes no responsibility for the sites.

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.

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

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

Links to: http://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.

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- 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 a full-time aide to handle nursing duties so that you can concentrate on solely being an emotional partner.

> To learn more, visit: https://caregiver.com/articles/aging-spouse-challenges

Links to: https://caregiver.com/articles/aging-spouse-challenges/

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

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- Because spousal cancer caregiving over time can create a more imbalanced relationship, it is important to remind your spouse that he or she is not completely incapable of giving back to you or, at the very least, expressing heartfelt gratitude.

- Between you and your spouse, try to treat the cancer 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: www.aasect.org/referral-directory

Links to: https://www.aasect.org/referral-directory

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Talking to loved ones **about difficult topics**

Difficult topics often make for difficult conversations, and many cancer Caregivers struggle with communication with their loved one or other family members. 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 it.

Not an actual
patient or caregiver.

When tab is selected, reader is brought to respective pages as follows:
Introduction - page 3
Phase 1: Confusion - page 11
Phase 2: Realization - page 25
Phase 3: Frustration - page 39
Phase 4: Acknowledgment - page 52
Phase 5: Collapse - page 64
Phase 6: Acceptance - page 76
Parents & Spouses - page 88
Important Resources - page 100

Important resources

> “Our life is what our thoughts make it.”
>
> *MARCUS AURELIUS*

Introduction
Phase 1 Confusion
Phase 2 Realization
Phase 3 Frustration
Phase 4 Acknowledgment
Phase 5 Collapse
Phase 6 Acceptance
Parents & spouses
Important resources

Important **resources**

In addition to awareness, preparedness is key to the Steady State of Cancer Caregiving. The following pages offer a list of resources along with helpful tools. Fill them out and print them as often as necessary.

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.

What's here:

Not an actual patient or caregiver.

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 your loved one's 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 are the treatment options available?
- What is the most effective treatment?
- What is likely to happen with and without treatment?
- Are there common complications associated with this condition?
- Who should I include in the Cancer Care Team?
- What is Survivorship Care, Hospice Care, and Palliative Care?

Medications

- What is/are the name(s) of the medication(s) you are prescribing?
- What is its benefit?
- What are the risks and side effects of taking the medication?
- What can I do to safely manage or alleviate these side effects at home?
- When and for which side effects should I contact you or a nurse for assistance?
- 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?

Cancer treatments

- When should my loved one begin chemotherapy/radiation/other therapy?
- Which drugs will he or she be given?
- How will the drugs be given to my loved one?
- How often will he or she need to get this type of treatment?
- How long will the treatments last?
- Where will he or she get this treatment?
- What's the goal of the chemotherapy/radiation/other therapy for his or her cancer?
- What are the chances that the cancer treatment will work?
- Are there other options that may help reach the same goals?
- How will we know if the treatment is working?
- What do we do if this treatment doesn't work?
- What are the risks and side effects of the chemotherapy/radiation/other therapy?
- How do these side effects compare with side effects of other treatments?
- What are the long-term risks?
- What can my loved one do to get ready for treatment and possibly decrease the chance of side effects?
- Which side effects should we report to you?
- Can my loved one take other medicines, vitamins, or supplements while receiving this treatment?
- Are there any other therapy options that may help me cope with side effects?
- Will my loved one need to change his or her diet during this period?

Questions to ask the doctor (continued)

Cancer treatments

- Can he or she drink alcohol?
- Can my loved one engage in physical activities? Exercise? Sexual activities?
- Will this treatment affect his or her ability to have children?
- Will he or she be able to work while receiving this treatment?
- Will he or she also need surgery, radiation, or both? If so, when and why? What results can we expect?
- If my loved one has chemo after surgery or radiation, will it kill any remaining cancer cells? Could chemo be used alone?

Questions to ask the doctor (continued)

Diet and exercise

- Are there any dietary changes necessary?
- Do you recommend any additional vitamins or supplements?
- How often should my loved one 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

- Who do I talk to about financial scenarios and assistance?
- What costs can we expect?
- Will insurance cover this surgery/test/treatment?
- What can we do to reduce costs?
- How much will this treatment cost?
- Will his or her health insurance cover it?
- If the insurance company asks for a second opinion, or if we would like to get one, can you suggest someone for my loved one to see?

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?

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)?
- Do you think we should look into psychology/social care?

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)	
Power of attorney—health care	
Power of attorney—finance	
Spouse’s/partner’s will (original)	
Safe combination	
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: ______________

Oncologist: ______________________________

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: ______________________________

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:

Name: ____________ Time: ____________

Agent name: ________________________

Notes: ________________________

____

Name: ____________ Time: ____________

Agent name: ________________________

Notes: ________________________

____

Name: ____________ Time: ____________

Agent name: ________________________

Notes: ________________________

____

Insurance company call log (continued)

Name: ______________________ Time: ______________________

Agent name: ____

Notes: ____

____

Name: ______________________ Time: ______________________

Agent name: ____

Notes: ____

____

Name: ______________________ Time: ______________________

Agent name: ____

Notes: ____

____

Name: ______________________ Time: ______________________

Agent name: ____

Notes: ____

____

Cancer-specific resources* for Caregivers

Breast cancer

Alamo Breast Cancer Foundation	www.alamobreastcancer.org 210-692-9535 (Helpline)
Avon Breast Cancer Crusade	www.avon.com/breast-cancer-crusade
Breastcancer.org	www.breastcancer.org 610-642-6550
BreastCancerTrials.org	www.breastcancertrials.org 888-282-7099
Dr. Susan Love Research Foundation	drsusanloveresearch.org 310-828-0060
Facing Our Risk of Cancer Empowered (FORCE)	www.facingourrisk.org 866-288-RISK (7475)
Inflammatory Breast Cancer Research Foundation	www.ibcresearch.org 877-786-7422
Komen for the Cure; National	www.komen.org 877-465-6636
Living Beyond Breast Cancer	www.lbbc.org 855-807-6386
Metastatic Breast Cancer Network	www.mbcn.org 888-500-0370
METAvivor Research and Support	www.metavivor.org 818-860-1226
SHARE	www.sharecancersupport.org 844-275-7427
Sharsheret	www.sharsheret.org 866-474-2774
Sisters Network	www.sistersnetworkinc.org 866-781-1808
Triple Negative Breast Cancer Foundation	www.tnbcfoundation.org 877-880-8622
Young Survival Coalition	www.youngsurvival.org 877-972-1011

Links to: http://www.alamobreastcancer.org/

Links to: https://www.avon.com/breast-cancer-crusade

Links to: https://www.breastcancer.org/

Links to: https://www.breastcancertrials.org/BCTIncludes/index.html;jsessionid=JzXQk_K-mIviAOQKBM-sOCfkKru_Ukp0AH7b-WnW.ip-10-20-10-73

Links to: https://www.towercancer.org/dr-susan-love-fund/

Links to: https://www.facingourrisk.org/

Links to: https://ibcresearch.org/

Links to: https://www.komen.org/

Links to: https://www.lbbc.org/

Links to: LInks to: https://mbcn.org/

Links to: https://www.metavivor.org/

Links to: https://www.sharecancersupport.org/

Links to: https://www.sharsheret.org/

Links to: http://www.sistersnetworkinc.org/

Links to: https://tnbcfoundation.org/

Links to: https://youngsurvival.org/

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Cancer-specific resources for Caregivers (continued)

Carcinoid/NET

Neuroendocrine Tumor Research Foundation	www.netrf.org 617-946-1780
Carcinoid Cancer Foundation	www.carcinoid.org 888-722-3132
Neuroendocrine Cancer Awareness Network	www.netcancerawareness.org 516-781-7814 866-850-9555
New Jersey Carcinoid Cancer Network	www.njcarcinoidnetwork.org

General cancer (Pan-tumor)

American Cancer Society - Cancer Action Network (policy)	www.fightcancer.org 202-661-5700
Cancer Support Community	www.cancersupportcommunity.org 888-793-9355
Crossroads 4 Hope	www.crossroads4hope.org 908-658-5400
Cancer*Care*	www.cancercare.org 800-813-HOPE (4673)
Milken Institute FasterCures	https://milkeninstitute.org/health/fastercures 202-336-8900
Friends of Cancer Research	www.friendsofcancerresearch.org 202-944-6700
Genetic Alliance	www.geneticalliance.org 202-966-5557
GRACE (Global Resource for Advancing Cancer Education)	www.cancergrace.org 888-501-1025
LIVESTRONG	www.livestrong.org 855-220-7777
National Coalition for Cancer Survivorship	www.canceradvocacy.org 877-NCCS-YES (622-7937)
National Patient Advocate Foundation (policy)	www.npaf.org 202-347-8009

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Cancer-specific resources for Caregivers (continued)

Patient Advocate Foundation	www.patientadvocate.org 800-532-5274
Prevent Cancer Foundation	www.preventcancer.org 800-227-2732
Research Advocacy Network	www.researchadvocacy.org 877-276-2187
Stupid Cancer (young adults)	www.stupidcancer.org 212-619-1040
Vital Options	www.vitaloptions.org 800-518-2354

LInks to: http://www.patientadvocate.org/
Links to: https://preventcancer.org/
Links to: https://www.researchadvocacy.org/
Links to: https://stupidcancer.org/
Links to: https://www.vitaloptions.org/

GIST

GIST Cancer Research Fund	www.gistinfo.org 305-944-4590
GIST Support International	www.gistsupport.org 215-340-9374

Links to: https://gistinfo.org/
Links to: https://www.gistsupport.org/

Iron Overload

Cooley's Anemia Foundation	www.thalassemia.org 212-279-8090
Sickle Cell Disease Association of America	www.sicklecelldisease.org 800-421-8453

Links to: https://thalassemia.org/
Links to: https://www.sicklecelldisease.org/

Leukemia & Lymphoma

International Waldenstrom's Macroglobulinemia Foundation (IWMF)	www.iwmf.com 941-927-4963
Leukemia & Lymphoma Society	www.lls.org 888-557-7177
Lymphoma Research Foundation	www.lymphoma.org 212-349-2910
TJ Martell Foundation	www.tjmartell.org 615-256-2002
The National CML Society	www.nationalcmlsociety.org

Links to: https://iwmf.com/
Links to: https://www.lls.org/
Links to: https://www.lymphoma.org/
Links to: https://tjmartell.org/
Links to: https://www.nationalcmlsociety.org/

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Cancer-specific resources for Caregivers (continued)

Lung cancer

Go 2 Foundation for Lung Cancer	www.go2foundation.org 1-800-298-2436
Lung Cancer Research Foundation	www.lungcancerresearchfoundation.org 212-588-1580
Lung Cancer Foundation of America	www.lcfamerica.org 323-741-4713
LUNGevity Foundation	www.lungevity.org 312-407-6100

Melanoma

AIM at Melanoma	www.aimatmelanoma.org 833-236-3635
Melanoma Research Foundation	www.melanoma.org 800-673-1290

Multiple myeloma

International Myeloma Foundation	www.myeloma.org 818-487-7455
Multiple Myeloma Research Foundation	www.themmrf.org 203-229-0464

Rare diseases

Acromegaly Community	www.acromegalycommunity.com 918-786-8209
Cushing's Research and Support Foundation	www.csrf.net
Every Life Foundation	www.everylifefoundation.org 415-884-0223
Global Genes	www.globalgenes.org 949-248-RARE (7273)
Magic Foundation	www.magicfoundation.org 800-362-4423
National Organization for Rare Diseases (NORD)	www.rarediseases.org 203-744-0100
Pituitary Network Association	www.pituitary.org 805-499-9973
Tuberous Sclerosis Alliance	www.tscalliance.org 800-225-6872

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Resources for other conditions*

AIDS	Centers for Disease Control and Prevention	Links to: https://www.cdc.gov/ www.cdc.gov 800-CDC-INFO (232-4636)
ALS	Amyotrophic Lateral Sclerosis Association	Links to: https://www.als.org/ www.als.org 800-782-4747
Alzheimer's disease	Alzheimer's Association	Links to: https://www.alz.org/ www.alz.org 800-272-3900
Cystic fibrosis	Cystic Fibrosis Foundation	Links to: https://www.cff.org/ www.cff.org 800-FIGHT-CF (344-4823)
Diabetes	American Diabetes Association	Links to: https://diabetes.org/ www.diabetes.org 800-342-2383
Elderly	USAging	Links to: http://www.usaging.org/ www.usaging.org 202-872-0888
Heart disease	American Heart Association	Links to: https://www.heart.org/ www.heart.org 800-242-8721

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Resources for other conditions (continued)

Lung disease

Links to: https://www.lung.org/

American Lung Association	www.lung.org 800-586-4872

Multiple sclerosis

Links to: https://www.nationalmssociety.org/

National Multiple Sclerosis Society	www.nationalmssociety.org 800-344-4867

Parkinson’s disease

Links to: https://www.parkinson.org/

National Parkinson Foundation	www.parkinson.org 800-473-4636

Stroke

Links to: https://www.stroke.org/

American Stroke Association	www.stroke.org 888-478-7653

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Often, prescription manufacturers offer support and savings to patients on treatment. You just have to ask. Give them a call or check online to see if you can start saving on monthly prescriptions.

Novartis Resources

We want to make sure you get the support you need for your specific disease. That's why Novartis is committed to helping make treatment as accessible as possible.

Novartis is committed to supporting patients throughout their treatment journey

Novartis Patient Support

Novartis Patient Support is a comprehensive program that is designed to help eligible patients start, stay, and save on treatment.

If you have prescription drug coverage, Novartis Patient Support can help guide you through the reimbursement process for certain Novartis medications. Most programs offer valuable patient support services, and some may help you if you cannot afford your out-of-pocket co-pay costs if you are privately insured. To learn more call [**1-888-NOW-NOVA**] or go to **Novartis Patient Support**

LInks to: https://www.novartis.com/us-en/patients-and-caregivers/patient-assistance/novartis-patient-support

Novartis Patient Assistance Foundation

Novartis Patient Assistance Foundation, Inc. (NPAF) is an independent, 501(c)(3) non-profit entity that provides certain medications at no cost to eligible patients who cannot afford the cost of their Novartis medication, are uninsured or have government insurance, and meet income guidelines and other eligibility criteria. NPAF does not provide product to individuals having insurance associated with any type of alternate funding program that conditions, restricts, or adjusts coverage based on application to NPAF or any other free goods program. Other terms and conditions may apply. To learn more go to: Novartis Patient Assistance Foundation [(**www.pap.novartis.com**)] or call [**1-800-277-2254**]

Links to: https://pap.novartis.com/

*Limitations apply. Offer is not valid under Medicare, Medicaid, or any other federal or state program. Novartis reserves the right to rescind, revoke, or amend this program without notice. For full Terms and Conditions go to [www.Copay.NovartisOncology.com].

Links to: https://www.copay.novartisoncology.com/

Additional support and programs*

Federal agencies and programs

Medicare	www.medicare.gov
Medicaid	www.medicaid.gov

Links to: https://www.medicare.gov/

Links to: https://www.medicaid.gov/

Additional Caregiver support

National Alliance for Caregiving	www.caregiving.org
Caregiver Action Network	www.caregiveraction.org
American Association of Retired Persons (AARP)	www.aarp.org
Mended Hearts	www.mendedhearts.org

Links to: https://www.caregiving.org/

Links to: https://www.caregiveraction.org/

Links to: https://www.aarp.org/

Links to: https://mendedhearts.org/

*Listing of an organization does not imply an endorsement by Novartis Pharmaceuticals Corporation. Links for external websites are independently operated and not managed by Novartis Pharmaceuticals Corporation. Novartis assumes no responsibility for the sites.

Caregiver’s checklist

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

Phase 1: **Confusion**

☐ Identify a core care team of health care professionals (*primary care doctor, oncologist, pharmacist, psychologist, social worker*) and personal supporters (*family, friends, neighbors*). Keep their contact information handy.

☐ Request that your loved one 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 cancer foundations for educational materials.

☐ Ask the primary care doctor, oncologist, nurse, or pharmacist questions you may have about medication routines, other therapy, cancer treatments, side effects, etc.

Phase 2: **Realization**

☐ Contact your loved one’s insurance company to find out about home health aide coverage and options. Refer to your Caregiver 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 Family Caregiver Council if there are any Caregiver support programs offered in your area.

☐ Try medication-management techniques to help you and your loved one stick with the routine, and use the Medication List to help stay on track.

Phase 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 your loved one for emergencies that require unexpected hospital stay.

Caregiver's checklist (continued)

Phase 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 to your loved one and other family members about long-term care plans.
- ☐ Consolidate medication prescriptions at a single pharmacy.

Phase 5: **Collapse**

- ☐ Join a local cancer 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 if your loved one can't be left alone.

Phase 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, like 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 local transportation offerings.

Notes

This is not the end.

Every day is a new beginning; a new day on your cancer caregiving journey. And while each one may present different experiences—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:

200 **Novartis Caregivers**

46 **Reports and websites**

30 **Family Caregivers**

5 **Category experts**

1 **Behavioral psychologist**

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

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