

Caregiver Guide

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Introduction

At Fred Hutchinson Cancer Center, we believe that caregivers are a valuable and important member of a patient's care team. We put together this Caregiver Guide, with the help of Fred Hutch caregivers, to help support you as you take on this important role. In it, you will find tips on how to be an effective caregiver and advice on how to continue caring for yourself while caring for someone else. We encourage you to keep this guide handy and refer to it throughout your time as a caregiver.

We also encourage you to read the patient guide or manual that the person you're caring for received from their care team. They may have received one of the following, depending on their treatment plan:

- **Guide to Your Care** (for General Oncology patients)
- **Transplant Manual** (for Blood and Marrow Transplant Program patients)
- **Your Guide to Immunotherapy** (for Bezos Family Immunotherapy Clinic patients)

Each of these manuals was created to help patients understand their treatment experience and serve as a resource throughout their time here. Visit our Patient Education web page at FredHutch.org/patient-education to find an electronic version or ask your care team for a hard copy.

Fred Hutch is an independent, nonprofit organization that also serves as the cancer program for UW Medicine. This unique relationship allows for enhanced care coordination with one of the world's leading integrated health systems.

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FredHutch.org

A letter from one caregiver to another

Dear fellow caregiver,

Being a caregiver to someone undergoing cancer treatment is an incredibly love-filled, yet daunting, task. You will lean on your community, stand by yourself, cry, laugh, break down, and hopefully feel supported as you do this amazing work. You will hear so much about how to best care for yourself during this time. You will find some information helpful, some useless, some brilliant, and some well-intentioned but out of touch with what is now your reality. There is no cookie-cutter mold for how to cope and thrive in this role. I hope you know that you are an invaluable part of your loved one's care team and that your voice and experience are vital.

Throughout this process you will need help. I found that the support I needed changed dramatically depending on treatment phase, constantly changing based on what phase my husband was going through. At times, taking care of yourself may seem overwhelming and more like another task to check off your list versus something that helps you relax and regroup. While taking care of yourself is extremely important, please don't feel guilty if your current self-care tools aren't serving you. Bottom line: it is OK to do whatever you need to do in order to stay sane, healthy, and present.

You may have to be the "go-to" person for family members, co-workers and friends. This will hopefully be an uplifting and energy-filling part of your experience. It can also feel draining if others are requiring support from you that you aren't prepared to give. I encourage you to trust yourself, be open to change, and try to remember that each person is bringing their own set of emotions, past experiences, and questions to the table. That being said, your main job as a caregiver is to care for your loved one and not everyone else all of the time. Having healthy boundaries will help you stay focused and well during this difficult time.

This handbook has some wonderful resources to help you with many aspects of this process. I wish you courage, strength, and the ability to advocate for your family the best way you know how. Above all else, please know that you are not alone.

With love and support,

Jennie Guiley

Jennie cared for her husband during his treatment at Fred Hutchinson Cancer Center. She is part of Fred Hutch's Patient and Family Advisor program and lives in Seattle with her husband and two kids.

Caring for someone else

What is a caregiver?

Being a caregiver means helping with the daily needs of another person. Being a caregiver can change daily. Some days you may find that you are able to balance all of the demands that come with being a caregiver and other days it can be difficult to find the time to do it all.

Caregiving can take a toll on your body, emotions, spirituality, and finances. It's important to take care of yourself so that you can cope with these changes. By eating healthy, exercising, relaxing, getting enough sleep, and asking for help, you will have more energy to take care of someone else and prevent personal health problems. Continue reading this guide to learn more about how to care for someone else while also focusing on yourself.

Examples of caregiver responsibilities

- Making arrangements
 - Transportation
 - Financial
 - Appointments
- Giving emotional support
 - Being physically present
 - Giving encouragement
 - Helping your loved one find ways to cope
- Doing chores
 - Cleaning
 - Cooking
 - Grocery shopping
- Being an advocate for the patient
 - Gathering information and making sure the right information is given to care team
 - Helping with decision-making
- Providing physical care
 - Bathing, dressing or shaving
 - Identifying changes in loved one's condition
 - Getting medical care when needed
 - Reporting symptoms to care team
 - Making sure medications are taken
 - Recording medications taken
 - Getting medical supplies
 - Helping with at-home medical care, such as central line care
- Supporting other people in the patient's life
 - Serving as a communication link with other family members or friends
 - Giving information to children
 - Providing childcare

Reference: [cancer.org/treatment/caregivers/caregiver-resource-guide.html](https://www.cancer.org/treatment/caregivers/caregiver-resource-guide.html)

Tips for taking care of someone else

While everyone's cancer journey is unique, there are some caregiving tips that apply to nearly everyone. Here are some we think you'll find helpful.

Social and emotional tips

- **Talk it out.** Typically, cancer does not move quickly, and it's important to take some time to process what's happening. Talk to your loved one about the decisions that need to be made right now, including second opinions and where to be treated.
- **Listen and learn.** During appointments, take notes or, with your care team's OK, record the conversation. If you have permission to talk with the care team yourself, you can; otherwise, let your loved one lead the conversation. Once the treatment plan has been agreed on, get the plan in writing. Ask questions about any points that you don't understand.
- **Be realistic about what's ahead.** Treatment can be tiring, both emotionally and physically, so try not to minimize what you or your loved one is going through. Keep in mind that people react differently to different treatments. Also know that the effects of chemo can grow over time. Your loved one may feel fine at the beginning of treatment but will likely feel worse before they feel better.
- **Kind gestures help.** Small gifts and cards can help lift your loved one's spirits. It's normal for your loved one to experience days when they feel lonely, afraid, or depressed. Giving them small things can lift their spirits and help them feel less alone.
- **Allow your loved one to express feelings.** As a caregiver, you want to be sure your loved one feels safe and comfortable expressing exactly how they feel. You don't want them to feel the need to be upbeat all the time.
- **Be honest with your loved one.** For instance, if you need to get outside help from a home health aide or hospice worker, include your loved one in the process. Ultimately, they should maintain as much independence and make as many decisions about their care as they can.

Practical tips

- **Call a family meeting.** Friends and family from near and far may want to be involved. Organize a family meeting, even by phone, to discuss who will do what. It's important for your loved one to be involved, too. Plan follow-up meetings or calls on a regular basis to make sure the caregiving plan is up to date, as plans may change during treatment.
- **Discuss legal and financial issues.** If your loved one hasn't already done so, they may want to take care of important affairs, such as wills, living wills, and medical power of attorney. Even if the cancer has a high cure rate, it's something everyone should do at some point. Also consider reviewing financial details, such as bank accounts, tax documents, stocks, bonds, mutual funds, and contact information for financial advisers.
- **Ask your care team questions.** We value, care and respect your input throughout your journey. We want you to feel empowered to ask questions and communicate changes in your loved one's body, mood and symptoms, because sharing these important details can make a real difference in your loved one's medical care.
- **Review the symptom sheets you receive and contact your care team** if your loved one has them. They can help you manage side effects at home.
- **Keep a list of what friends and family can do and assign tasks.** For example, one person could drive your loved one to an appointment, another could make a meal, and another could go to the grocery store. Some people have more time than others, and that is where a list can be helpful. Ask your family and friends for help before you are too tired.
- **Develop a schedule each day or week that includes goals for that time period.** Share the schedule with others who are helping you. Having a schedule with clear goals helps keep everyone on the same page and can help decrease the tension within a family.
- **Organize your day into manageable segments.** Fill in the schedule template at the end of the guide to start.
- **Tell your care team if you need more support.** Your care team works closely with specialists throughout Fred Hutch, including social workers, dietitians and many others, who are here to help you. These specialists become part of your extended care team.

Caring for yourself

What is self-care?

Self-care means taking care of yourself so that you can stay healthy, do your job, help and care for others, and do all the things you need to and want to accomplish. Self-care is even more important when you're focused on caring for someone else.

Examples of self-care responsibilities

Physical self-care

- Going for a walk
- Taking a bath
- Getting enough sleep (7–9 hours per night)
- Eating nourishing foods

Psychological self-care

- Practicing mindfulness
- Reading a book
- Learning a new skill
- Doing a digital detox (not looking at your phone or other electronics)

Emotional self-care

- Saying no
- Making time for reflecting on feelings
- Practicing self-compassion
- Being aware of your emotional boundaries

Social self-care

- Honoring your commitments to other people
- Asking for help when you need it
- Meeting new people
- Spending time with family and friends

Spiritual self-care

- Meditating
- Reflecting in a journal
- Going on a retreat
- Walking in nature

Reference: moderntherapy.online/blog-2/areas-of-self-care

Caring for yourself, continued

We realize that some days taking care of yourself is going to feel like more of a burden than a relief. On those days, try to do something small. For instance:

- Take the stairs instead of the elevator for your exercise that day
- Talk to a friend or read a breezy novel for a mental escape
- Feel the drops of water land on your skin or focus on the sensation of brushing your teeth for your daily mindfulness

Whatever you do, the overall goal is to be kind to yourself, give yourself grace, and acknowledge that you are doing what you can at that moment for yourself and for the person you're caring for.

Caregiver bill of rights

You can start your self-care process by making a commitment to yourself to follow the Caregiver Bill of Rights. Feel free to add your own rights to the list. Read it to yourself daily.

I have the right to:

- Maintain parts of my own life that do not include the person I care for, just as I would if they were healthy. I know that I do everything that I reasonably can for this person, and I have the right to do some things for myself.
- Get angry, be depressed, and express other difficult feelings occasionally.
- Reject any attempt by my relative (either conscious or unconscious) to manipulate me through guilt, anger, or depression.
- Receive consideration, affection, forgiveness, and acceptance for what I do for my loved one for as long as I offer these qualities in return.
- Take pride in what I am accomplishing and applaud the courage it has sometimes taken to meet my loved one's needs.
- Protect my individuality and my right to make a life for myself that will sustain me in the time when my relative no longer needs my full-time help.
- Expect and demand that as new strides are made in finding resources to help physically and mentally impaired older persons in our country, similar strides will be made toward helping and supporting caregivers.

— Jo Horne, author of *Caregiving: Helping an Aging Loved One*

Tips for taking care of yourself

Practical, emotional and social tips

Accept help. If friends or neighbors ask what they can do to help, tell them. Keep a list on hand, so you can let them know exactly what you need. If friends or relatives are not available to help for a few hours, hire someone or find adult day care. See the “Respite care at home” page of this guide for a list of local organizations that may be able to help. In addition, the U.S. Administration on Aging offers a national database of elder care providers at eldercare.acl.gov.

Get some sleep. To overcome insomnia, experts suggest everything from guided imagery and relaxation techniques to acupuncture and even warm milk. Cutting back on late afternoon caffeine and boosting your exercise, especially yoga, may also help you to sleep better. Sometimes it helps to write down your worries and “release” them for the day before heading to bed. If all else fails, it may be time to talk to the doctor about a sleep aid. See the “Sleep problems and healthy sleep habits” page of this guide for tips on sleeping.

Keep up your health. With everything they have to do in a day, caregivers often neglect basic health maintenance. Some simple things to do for yourself include eating regular meals that are rich in fruits and vegetables, staying hydrated, and exercising, even if it’s a brisk 15-minute walk each day (increase it to 30 to 45 minutes when you can). Find someone to sit with the person you’re caring for so you can keep your regular appointments for dental cleanings, health screenings, and annual checkups, too.

Find meaning. If you can take your experience with cancer and find meaning and learn from it, you may have less depression and anxiety. Work on your personal growth. Participate in an art therapy workshop, begin a journal, talk with a counselor, or lean on your faith community.

Do not hold yourself accountable for the overall outcome. Oftentimes, caregivers blame themselves if the person they’re caring for isn’t doing well. There is only so much you can control. You cannot make the person you’re caring for feel happy, particularly when they are going through really difficult treatments. You cannot force them to eat if they refuse to. You cannot make sure they survive or are cured of cancer. You can ask for help when you need it though, and we encourage you to do that.

Emotional resilience

Emotional resilience is your ability to move through stressful situations in a healthy way. You can build your emotional resilience through effort and practice by taking these steps:

Reach out and make connections. Caring for someone full-time can lead to feelings of panic, despair, and isolation. And after the initial crisis of diagnosis and treatment, there's often a lingering worry that the cancer could return. Reach out to friends, family, online groups, and support organizations to help reduce feelings of isolation. Accepting help and support from those who care about you and will listen to you strengthens resilience.

For information on support groups, contact Fred Hutch's Patient and Family Resource Center staff at (206) 606-2081 or patientresourcectr@seattlecca.org. You can also visit FredHutch.org/resource-library.

Avoid seeing crises as problems you can't overcome. You can't change the fact that highly stressful events happen, but you can change how you interpret and respond to these events. Try looking beyond the present and into the future, where circumstances may be better. Notice any subtle ways that you might already feel better as you deal with difficult situations.

Accept that change is a part of living. Certain goals may no longer be achievable as a result of your situation. Accepting circumstances that cannot be changed can help you focus on circumstances that you can change.

Move toward your goals. Develop some realistic goals. Do something regularly — even if it seems like a small accomplishment — that enables you to move toward your goals. Instead of focusing on tasks that seem unachievable, ask yourself, “What's one thing I know I can accomplish today that helps me move in the direction I want to go?”

Take action. Act on adverse situations as much as you can. Take action, rather than detaching completely from problems and stresses and wishing they would just go away.

Emotional resilience, continued

Look for opportunities for self-discovery. People often learn something about themselves and may find that they have grown in some respect as a result of their struggle with loss. Many people who have experienced tragedies and hardship have reported better relationships, a greater sense of strength even while feeling vulnerable, an increased sense of self-worth, a more developed spirituality and heightened appreciation for life.

Nurture a positive view of yourself. Developing confidence in your ability to solve problems and trusting your instincts helps build resilience.

Keep things in perspective. Even when facing very painful events, try to consider the stressful situation in broader context and keep a long-term perspective. Avoid blowing the event out of proportion.

Maintain a hopeful outlook. An optimistic outlook allows you to see that good things will happen in your life. Instead of worrying about what you fear, visualize what you want and hope for.

Reference: [verywellmind.com/emotional-resilience-is-a-trait-you-can-develop-3145235#:~:text=Emotional%20resilience%20refers%20to%20one's,changes%2C%20both%20major%20and%20minor.](https://www.verywellmind.com/emotional-resilience-is-a-trait-you-can-develop-3145235#:~:text=Emotional%20resilience%20refers%20to%20one's,changes%2C%20both%20major%20and%20minor.)

Caregiver burnout

Caregiver burnout happens when you are physically, emotionally, and mentally exhausted. Your attitude may also change from positive and caring to negative and unconcerned. You can get “burned out” when you don’t get the help you need or if you try to do too much. Caregivers who are burned out may experience fatigue, stress, anxiety, and depression. Many caregivers also feel guilty if they spend time on themselves rather than the person they’re caring for. This section explains signs of burnout, how it happens, and offers steps to get help.

Signs of caregiver burnout

- Irritability
- Insomnia
- Physical complaints
- Fatigue
- Decreased motivation
- Anger
- Resentment
- Emotional exhaustion
- Difficulty delegating
- Perfectionism
- Being a “giver” rather than “receiver”
- Not seeing friends or family
- Discontinuing most or all of your regular activities or hobbies

How does burnout occur?

- Lack of clear job role definition
- Poor communication
- Uncertain rewards
- High expectations
- Difficulty saying no
- Feeling of needing to prove oneself
- Self-sacrifice
- Commitment, dedication, and idealism
- List all tasks that need to get done
- Group your list into categories
- Write down your worries
- Know what you can and cannot control
- Get together with a friend
- Pat yourself on the back
- Ask someone for help – asking for help is a sign of strength, not weakness

Steps to getting help

Self-care quiz

Take this quiz on a regular basis. If you answer “false” more than two times, you may have caregiver burnout and should follow the tips in the “Caring for yourself” section and read through the “Resources” section at the end of this guide.

How are you doing?

- | | | |
|----------------------------|------|-------|
| I feel rested and calm. | True | False |
| I am getting enough sleep. | True | False |
| I have someone to talk to. | True | False |
| I am eating right. | True | False |
| I am exercising regularly. | True | False |

Helping children cope when someone they love has cancer

This section offers information to help children understand what's happening when someone they love has cancer. It also offers ways to help them process their thoughts and emotions. If, after reading this section, you would like to meet with a Child Life Specialist, please call (206) 606-7621. Please note that throughout this section we use the term "your child," but this information is meant for anyone who is close to a child whose loved one has been impacted by cancer.

Common questions your child may ask

Will I get cancer?

Cancer is not contagious. You cannot "catch" cancer.

Did something I do cause the cancer?

No. Cancer can just happen. Scientists are doing research to understand this better, but nothing you did or thought caused the cancer.

Is cancer treatment a punishment?

No. Cancer treatment is not a punishment. It is a way to get rid of bad cancer cells in the body. Even though it can make you feel bad for a while, it makes your body healthier in the long run.

A conversation about cancer cells is often helpful to help children understand the way treatment works, for example:

"Your body is made up of tiny building blocks called cells. Cancer happens when cells grow too fast and makes other cancer cells too quickly. This makes the body not work right. Chemotherapy kills these fast-growing cells.

During surgery, the doctor takes out the group of cancer cells. Chemotherapy can affect other fast-growing cells in the body such as hair cells and cells in the stomach; this is why a person may lose their hair and feel sick to their stomach during treatment. They will feel better and their hair will grow back after the chemotherapy treatment ends."

Are you going to die from cancer?

Your answer to this question will change based on your child's age, your family's beliefs, and your situation. A social worker or other health professional can help you sort through this, for example:

“We are working very hard for me or <name of loved one> to get well. I will let you know if this changes or if I am worried about <name of loved one> dying. I also want you to tell me when you are worried. What would you worry about most if <name of loved one> died?”

A child may have specific fears that he or she wants to talk about, for example:

“Where would my room be? Who would watch me after school?”

When and how much do I tell my child?

You know your child best. How you talk with your child about cancer will vary based on your knowledge of your child and your family's culture, faith, and beliefs about cancer. People have many myths about cancer and treatment. Stick with the facts. Here are some suggestions for talking to your child.

When to talk to your child

- Talk to them early. Children can usually sense when something is wrong and often imagine the worst if they don't know what is happening. Teaching children early about your diagnosis helps them feel included and helps them understand the changes they see.
- While teaching your child early is important, try to learn as much as you can about the illness and treatment plan, including side effects and the schedule of treatment. This will help prepare you to answer their questions.
- Choose a time to talk to your child when you are calm. This will help you support your child with their emotional reaction. Know that your child may be upset by the information or hardly react at all. Children often need to absorb this information over time.
- Invite a professional or a close family member to help prepare you mentally and emotionally for a conversation with your child. If needed, they may help you discuss the illness with your child. You or another loved one should be with the child for support and security if another person provides the information.

How to talk to your child

- Begin with what the child sees and knows, for example: “You know how your aunt has been grouchy and sleeping a lot?”
- Use the actual name of the disease, including the word “cancer,” so the child becomes familiar with it. This will help them feel prepared for the terminology they will hear from others.
- Remind your child that there are many different types of cancer and treatments. They may think exactly what happened to another relative or friend with cancer will happen to you. It may be very different.
- Use age-appropriate language they can understand about where in the body the disease is, how the disease will be treated, and how this will affect their life, including changes in family system. See “How children process information by age” section for more about this.
- The amount of information children want versus what they can cope with varies. Your goal is to give enough information that will address their fears and give them a sense of security amid the upcoming changes. Let their feelings guide you.
- Be truthful about things you cannot answer or offer. Sometimes telling them that everything will work out well is not possible. Make sure they know that they will be taken care of no matter what. Use this opportunity to tell your child about how you cope with the unknown.
- Encourage your child to ask questions. You may need to answer the same question many times.

Activities for your child

It may be helpful to have your child do something to help them work through their emotions. You can ask your child to:

- Draw a picture that completes this sentence: “When I feel sad I...” Your goal is to get them to draw the emotion and tell you about a time when they felt that way.
- Journal or scrapbook about their experience. They can include the best and worst parts of each day.
- Create artwork (draw or paint a picture, for instance) for their loved one who is ill.
- Make “books” about the illness for their younger siblings.

Meeting your needs

It is extremely challenging to parent and manage cancer treatment and side effects. Take care of yourself by doing the following:

- Recognize your limits and adjust expectations of yourself.
- Set aside time every day for yourself.
- Eat healthy foods.
- Stay active and get enough sleep.
- Let people help you; keep a list of specific things others can do.
- Lean on friends, family members, support groups, and professionals for emotional support.

Meeting your child's needs

General

- Be open to discussion, anyplace, anytime. Children may have a question when you least expect it.
- Allow your child to see the treatment clinic or hospital if they show interest in going. Prepare them for what to expect before the visit.
- Your child will cope with this in their own unique way. Ask how they are doing and look at their behavior for clues.
- Your time is one of the greatest ways to show your love. Make one-on-one time a priority for each child.
- Allow your child to “help” in ways that are meaningful to them. For example, drawing a “get well” picture, or filling your water pitcher each morning.
- Discuss changes in routine and what your child can expect.
- Let friends and family help fill in gaps, like going to your child's soccer game.
- Make everyday activities more creative and fun, for example: have a home “picnic” at mealtime, watch funny movies at night, or work on a family art project together.

Social and developmental

- Help your child maintain as much contact as they can with friends, family, and others they care about (in person or by phone, text, email or letters).
- Maintain learning opportunities and structure through formal school or tutoring.
- After discussing it with your child, alert school counselors and teachers about the situation and your child's current needs.
- Discuss any family privacy issues and expectations with your family members. Let them know what is and is not okay to talk about outside of your family.
- It is normal for your child to act younger and test limits during this period. They may be looking for attention from you or a clear sense of safety and security during this period.
- Discipline is hard to maintain but is very important to help your child continue to develop and function well with family, peers, and school during and after treatment.
- Set clear expectations for your child during treatment and transition times. You and your child may need to be flexible with rules and routines during stressful periods (for example, bedtime).
- Discuss any changes in rules and routine with your child's caregivers. It is important to maintain as much consistency in your child's care and discipline plan as possible. For example, grandparents' rules and routines should be similar yours.

How children process information by age

This section offers insight into how your child may process information based on their age and stage. Please keep in mind that your child may fit into part of or more than one of these groups:

Infant and toddler age children (birth–2 years old):

- Do not understand the concept of illness; however, they do notice physical changes in caregiver, for example: hair loss, nausea, vomiting, mood changes.
- React to caregiver's emotions; can sense and respond to caregiver's anxiety, sadness, stress, etc.
- May develop changes in their eating/sleeping habits, mood and skin related to stress, for example: develop a rash or be difficult to soothe.

Infant and toddler age children, continued

- Notice and are sensitive to changes in routine; notice caregiver's absence and/or the presence of an unfamiliar adult. Try to have infants/toddlers cared for by trusted adults that are familiar to them.
- Leave them with a familiar blanket or object to ease separation anxiety.
- Give infants/toddlers lots of physical contact, for example: hugging and holding.
- If infants/toddlers are stressed or irritable, try to calm them with soft, relaxing music.

Preschool age children (3–5 years old):

- Tend to be egocentric; believe that the world revolves around them and care mostly about how the illness affects them.
- Are inclined to have magical thoughts; think they have the power and ability to control things, for example: think they can cause someone's illness by having bad thoughts about that person or by misbehaving.
- Are good at expressing feelings/emotions through play and sometimes need help identifying feelings.
- Tend to understand well when dolls, pictures and books are used to explain things.
- Need reassurance that someone will always be there to take care of them.
- May react with sadness or may seem indifferent.
- May react to illness by having behavior problems, for example: will act out more for attention or act younger in terms of development, for example: bedwetting, clinginess.
- Often believe that death is reversible and that a person who has died will/can come back.

Grade school age children (6–11 years old):

- May want to do some research about disease on their own.
- Start to understand that death is permanent.
- May want to know more about treatment, for example: side effects, physical changes.
- May react by being sad, mad, anxious and/or irritable; have physical complaints or headache, stomachache, and more; may be angry towards sick loved one; have poor concentration; or have difficulty adapting to changes in routine.

Teenagers (12 years old and above):

- Are capable of abstract thinking; understand ethics and ideas they cannot see.
- Tend to have a need for independence.
- Can sometimes deny feelings to avoid talking to you about them.
- Are capable of thinking like adults.
- May want a lot of details.
- Try to encourage them to talk about their feelings but realize they may be more comfortable talking to a friend, a professional, or another trusted person.
- Try to assure them that you want them to have normal activities outside of the family.
- Watch for signs of them trying to take on too much responsibility or parenting younger sibs.
- May react with anger, rebellion, depression and anxiety, withdrawal, physical symptoms such as: stomachaches and headaches, keeping feelings to themselves.

Resources for helping your children cope

The resources below were used to help create this section and may be helpful to you.

For adults

- Cancer in the Family: Helping Children Cope with a Parent’s Illness by Joan F. Hermann, Katherine V. Bruss (Editor), Joy L. Fincannon, pages 20-21.
- Can I Still Kiss You? Answering Your Children’s Questions About Cancer, by Neil Russell
- How to Help Children Through a Parent’s Serious Illness, by Kathleen McCue, with Ron Bonn
- Frankly Speaking about Cancer, What do I tell the Kids? Cancer Support Community, cancersupportcommunity.org
- When a Parent Has Cancer: A Guide to Caring for Your Children, by Wendy S. Harpham

For teens

- When Your Parent has Cancer, A guide for Teens, National Cancer Institute cancer.gov/publications/patient-education/when-your-parent-has-cancer.pdf

For children

- Art with Heart | Seattle-based group that uses art therapy to help kids deal with crisis artwithheart.org

We recommend that you or another adult read these with your child:

- The Invisible String, by Patrice Karst
- The Year My Mother Was Bald, by Ann Speltz, Kate Sternberg (Illustrator)
- Tickles Tabitha’s Cancer-Tankerous Mommy, by Amelia Frahm, Elizabeth Schultz (Illustrator)
- What Is Cancer Anyway? Explaining Cancer to Children of All Ages, by Karen L. Carney
- When Someone You Love Is Being Treated For Cancer, by the National Cancer Institute
- You are the Best Medicine, by Julie Clark

Supportive Care Services

As a caregiver, you have access to Fred Hutch's Social Work and Spiritual Health teams, among other supportive care services. Social workers and Spiritual Health advisors specialize in providing the type of emotional support described below.

If you would like to meet with a social worker or spiritual health advisor, please talk with your care team. For a full list of supportive care services offered at Fred Hutch, please ask your care team for the Supportive Care Services brochure or visit seattlecca.org/services.

Social Work

Social workers support caregivers as they cope with grief and loss, role changes, family dynamics, the challenges of caring for someone with a serious, chronic illness, and related emotional issues. Social workers help with crisis intervention for families experiencing acute distress related to changes in their loved one's medical condition, death and dying, or other stressful life events. Social workers also are available for follow-up grief counseling for families who have lost a loved one, and for end-of-life and funeral planning.

Spiritual Health

Being a caregiver to someone with a serious illness can be a painful, frightening, and isolating experience full of uncertainties and loss. Sometimes illness can push one to the point of experiencing spiritual and emotional chaos, pain and distress. But it can also be an opportunity to celebrate and change in new ways.

Spiritual health clinicians welcome the opportunity to be:

- An empathic listener and conversational partner as you seek, question and explore
- A comforter as you grieve and sounding board as you make tough decisions
- A conversational partner to talk about dying, death and afterlife
- A celebrator when you have good news
- A provider of religious rituals such as anointing, communion, prayer and blessings
- A resource for inspirational literature, sacred texts and meditation tapes
- A connector to a local faith community, including places of worship

Mind-body relaxation exercises

Research suggests that practicing mind-body relaxation daily helps reduce the physical and emotional effects of the stress hormones. This helps us sleep better and stay healthier during stressful times and throughout your life. Mind-body medicine comes in many forms, but each form gives you the ability to access a relaxation response in your body. This section offers videos and apps with exercises and three relaxation exercises: the 4-7-8 breath, soft belly breathing, and progressive muscle relaxation.

Videos and apps

- Visit bit.ly/10MinuteMeditation (url is case sensitive) to watch our video playlist of mind-body relaxation practices.
- Visit FredHutch.org/patient-education and search for the handout Mind-Body Relaxation Resources (or ask your care team for the handout), which has a list of relaxation techniques and a video link for each one.

The 4-7-8 breath

You can do this exercise seated or lying down.

1. Take a deep breath in to the count of 4.
2. Hold your breath to the count of 7.
3. Exhale to the count of 8.
4. Repeat this breath cycle 4 times and then stop.

It is best to return to normal breathing after 4 breaths; however, you may repeat this cycle of 4 breaths throughout the day when you feel stress, anxiety or worry. You can also use it to help you try to fall asleep.

The 4-7-8 breath is adapted from Dr. Andrew Weil, a medical doctor and the founder and director of the Andrew Weil Center for Integrative Medicine.

Soft belly breathing

This is a simple and ancient practice that has been used in yoga to help access the relaxation response in the body. You can do this exercise in any position.

1. Place your hand on your lower abdomen.
2. Breathe in through your nose as gently and deeply as you can into your lower abdomen, feeling your hand rise up as you breath in. As you inhale, think “soft”, allowing your belly to receive the breath.
3. Do not hold your breath but allow the breath to be slowly released through your mouth. On the out breath, think “belly,” letting go of any resistance or holding.
4. Repeat this breath cycle four times.

This practice engages the vagal nerve which has a calming effect on the nervous system, including the thinking brain.

Passive progressive muscle relaxation

You can do this exercise seated or lying down, with your neck supported and your hands and feet in a comfortable position if possible.

1. Close your eyes.
2. Breathe through your nose into your lower abdomen and then breathe out through your mouth slowly. Do this 3 times.
3. Now bring your attention to your forehead and allow those small muscles to stretch out and relax.
4. Then feel that relaxation flow over your eyelids, over the bridge of your nose and into your cheeks.
5. Feel that relaxation flow into your tongue and jaw. Even the little muscles in your scalp are stretching out and relaxing.
6. Now bring your awareness to your neck and shoulders.
7. Any tension or tightness in that area dissipates. Feel it drift away.
8. Now feel that relaxation flow into your chest, stomach and abdomen.

Passive progressive muscle relaxation, continued

9. Bring your awareness to the base of your neck and feel that relaxation flow over your entire back.
10. Feel that relaxation flow from your shoulders all the way down your arms into your hands and fingers.
11. Feels that relaxation move into your hips and all the way down your legs into your feet and toes.
12. Imagine any tension or tightness that remains in your body flowing out the bottoms of your feet and drifting away.

Sleep problems and healthy sleep habits

Many people have problems sleeping. When you don't get good sleep, it can affect your quality of life and ability to do daily activities. Sleeping well on a regular basis is important for your health. By practicing a few good habits, you can improve the quality of your sleep. This handout explains what causes sleep problems, when to contact your care team, and what you can do at home.

What causes sleep problems?

- Cancer and its treatments
- Medications related to non-cancer conditions
- Side effects related to cancer and its treatment
- Anxiety and depression
- Pain
- Restless leg syndrome
- Sleep apnea
- Lifestyle habits including caffeine (especially later in the day), not getting enough exercise, being exposed to too much noise or screen time

How to create healthy sleep habits

Create a peaceful sleep space

- Create an inviting and soothing sleeping space.
- Keep it dark, quiet, and cool (less than 68°F).

Quiet your body

- Avoid caffeine late in the day.
- Avoid moderate to intense exercise for a few hours before bedtime.
- Make time to slow down — take a warm bath with Epsom salts and aromatherapy, write in a gratitude journal, do gentle yoga, meditate, practice intimacy.
- Check to see if your medications have sleep side effects.

Use dusk and dark

- Dim lights a few hours before bed; sleep in total darkness.
- Use blue light reduction applications, devices, or screen protectors on your electronic devices (such as on your smartphone, tablet, computer screen, TV).

Recognize your wakefulness

- Go to bed only when you feel sleepy.
- When you are ready to sleep, create separation from the waking world (avoid watching the clock or using electronic devices).
- If you can't sleep, get up and sit in a comfortable spot until you feel sleepy again. Try progressive muscle relaxation with soft belly breathing or another mind-body exercise.

Surrender to sleep

- Ask your primary care or integrative medicine provider about evidence based botanical natural sleep aids.
- Instead of “going to sleep”, think about “letting go of being awake”.

Wake up mindfully

- Wake up slowly.
- Notice your morning thoughts and memories of your dreams.
- Set an intention for the day.
- Turn on the lights, or use daylight or a light box to energize your morning.
- Try waking at the same time each day.

Healthy sleep resources

- Health Journey's guided imagery for sleep: healthjourneys.com
- “Healing Sleep: Discover the Restorative Power of Sleep, Dreams, and Awakening” by Rubin Naimen, PhD
- American Cancer Society: Sleep Problems at [cancer.org/treatment/treatments-and-side-effects/physical-side-effects/sleep-problems.html](https://www.cancer.org/treatment/treatments-and-side-effects/physical-side-effects/sleep-problems.html)

Safe lifting

As a caregiver, you may be responsible for lifting more and different kinds of objects than you normally would. You can easily hurt your back when you lift something the wrong way. Read the tips below to learn how to stay safe while lifting, including learning when to ask for help.

Tips for safe lifting

- **Plan and prepare:** Before you lift, clear your path and plan your move.
- **Wide base:** Make sure your legs are shoulder-width apart. Keep your back straight.
- **Keep load close:** Stand close to the load and center yourself over it with your feet shoulder-width apart. Keeping the load close to your body lowers the strain on your lower back. Get a good grasp on the load with both hands.
- **Use your core abdominal muscles:** Tighten your abdominal muscles. As you tighten these muscles it will help keep your spine from shifting as you lift.
- **Lift with your legs and avoid bending over:** Make your legs do the majority of the work. Keeping your back straight, bend your knees and squat down. With the load close to your body, use your leg muscles to stand up lifting the load. When lowering the load, again bend your knees using only your leg muscles and place load in the desired location.
- **Avoid twisting:** Turn with your feet, not your back. Take small steps with your feet turning until you are in the correct position. Your feet and shoulders/head should always face the same direction.
- **Know your limits.** Never try to lift something that is too heavy for you. It's always better to get help. If you are having trouble helping the person you're caring for due to the strain of lifting, talk with your care team.
- **Ask for help:** Always get help if you need it and use lift devices whenever they are available.

More information

Ask your care team for a referral to Fred Hutch Physical Therapy to teach you how to lift and the proper body mechanics to keep you and the person you're caring for safe.

Respite care at home

A respite is an interval of rest or relief. Respite services include meal assistance, dressing assistance, medication supervision, laundry, grocery shopping, light housekeeping, and companionship. Respite care allows you to take some time for yourself.

Respite assistance usually is not covered by insurance. Please check with your nurse and social worker for additional information regarding respite care. Inclusion on this list does not mean endorsement by Fred Hutch. Exact responsibilities and payment plans need to be negotiated between you and the agency. Most agencies need 48 hours to accommodate a particular request.

Here is a brief list of home assistance services to assist with your homecare planning:

Care at Home of WA.(206) 932-5170 or (206) 937-3100

CareForce(425) 712-1999

Catholic Community Services(206) 328-5696

Family Best Care(425) 647-8510

Family Resource Home Care.(206) 545-1092

Fedelta Care Solutions(206) 362-2366

Homewatch Caregivers(206) 363-4599

Jewish Family Service.(206) 461-3240

Maxim Healthcare Services.(206) 985-4625

ResCare HomeCare Services(206) 368-7667 North Seattle
 (206) 329-4695 South Seattle

Right at Home(206) 774-1100

Synergy HomeCare.(206) 420-4934

Visiting Angels1 (800) 365-4189

Questions to ask:

- Is there a different rate depending on the number of hours?
- If the escort is scheduled to drive, does the person have a driver’s license?
- Is there someone to call for a reference?

Family Medical Leave Act (FMLA) and Disability

You or the person you're caring for may need to take medical leave or disability during treatment. Following the below steps to apply for FMLA or disability will make it easier for your care team to help you.

Steps for submitting paperwork to your care team

1. Get any forms needed for medical leave from your employer or the employer of the person you're caring for. You may need to talk with the human resources department of your company to get these forms.
2. Make sure the patient or caregiver portion of the form(s) is filled out before giving the form(s) to your Fred Hutch care team. This includes filling out the section below.
3. Bring any FMLA, disability or other paperwork needed for medical leave to your next appointment.
4. If you are unable to bring these forms to an appointment, please fax your care team at least one week before the paperwork is due.
5. Your care team will contact you if a phone consult or visit is needed.
6. Please give your care team 1 week to respond to your request process. We will fax your completed paperwork to your employer and mail you a copy.

Please fill out this section and attach it to your FMLA or disability paperwork

Today's date: _____ Name of patient: _____

Physician treating patient: _____ U#: _____

Caregiver: _____ (if forms are for someone other than patient)

Date forms needed by: _____

Employer: _____

Employer's contact for paperwork: _____

Employer's contact phone: _____ Employer's contact fax: _____

Employer's mailing address _____

Employee reference or case number (if known): _____

Your mailing address: _____

Daily caregiving schedule template

Time	Activity	Issues/Symptoms
7 am		
8 am		
9 am		
10 am		
11 am		
12 pm		
1 pm		
2 pm		
3 pm		
4 pm		
5 pm		

Medication schedule template

Medication	Purpose	Dose	8-9 am	12-1 pm	4-5 pm	8-9 pm

Other caregiver resources

Apps

Search for these apps in your app store:

- My Pillbox
- Carezone (you can also visit [carezone.com](https://www.carezone.com))

Articles, booklets and webpages

- Caring for the Caregiver
[cancer.gov/cancertopics/coping/caring-for-the-caregiver](https://www.cancer.gov/cancertopics/coping/caring-for-the-caregiver)
- Facing Forward - Life After Cancer Treatment
[cancer.gov/cancertopics/coping/life-after-treatment](https://www.cancer.gov/cancertopics/coping/life-after-treatment)
- Guide for Family Caregivers in Cancer
[cancer.gov/about-cancer/coping/family-friends/family-caregivers-pdq](https://www.cancer.gov/about-cancer/coping/family-friends/family-caregivers-pdq)
- So Far Away - Twenty Questions and Answers about Long-Distance Caregiving
order.nia.nih.gov/sites/default/files/2017-07/L-D-Caregiving_508.pdf
- Taking Time: Support for People with Cancer
[cancer.gov/publications/patient-education/taking-time](https://www.cancer.gov/publications/patient-education/taking-time)
- When Someone You Love is Being Treated for Cancer
[cancer.gov/cancertopics/coping/when-someone-you-love-is-treated](https://www.cancer.gov/cancertopics/coping/when-someone-you-love-is-treated)
- Caregivers' Guide for Bone Marrow/Stem Cell Transplant: Practical Perspectives
nbmtlink.org/documents/cg2.pdf

Books

- American Cancer Society: Complete Guide to Family Caregiving by Julia A. Bucher, Peter S. Houts, and Terri Ades
- When Someone You Love Has Cancer by Cecil Murphey
- Cancer Caregiving A to Z, American Cancer Society
- How to Help Your Friend with Cancer by Colleen Dolan Fullbright

Communicating with friends and family

- [Caringbridge.org](https://www.caringbridge.org)
- [Caringvillage.com](https://www.caringvillage.com)

Disability and employment rights

- Employment Rights Cancer and the Americans with Disabilities Act
[Eeoc.gov/laws/types/cancer.cfm](https://www.eeoc.gov/laws/types/cancer.cfm)
- Job Accommodation Network
[Askjan.org](https://www.asbjan.org)
- Cancer Legal Resource Center
[Thedrlc.org/cancer/](https://www.thedrlc.org/cancer/)
- Washington Paid Family & Medical Leave
[Paidleave.wa.gov/](https://www.paidleave.wa.gov/)

Organizing daily tasks, meals and other activities

- [Lotsahelpinghands.com](https://www.lotsahelpinghands.com)
- [Mealtrain.com](https://www.mealtrain.com)
- [Standwith.com](https://www.standwith.com)
- [Cleaningforareason.org](https://www.cleaningforareason.org)

Support organizations

- [Caregiver.com](https://www.caregiver.com)
- [Caregiver.org](https://www.caregiver.org)
- [Wellspouse.org](https://www.wellspouse.org)
- [Cancerhopenetwork.org](https://www.cancerhopenetwork.org)
- [4thangel.ccf.org](https://www.4thangel.ccf.org)
- [Cancercare.org/tagged/caregiving](https://www.cancercare.org/tagged/caregiving)
- [lmermanangels.org](https://www.lmermanangels.org)

