

## Caregiver Guide



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## **Introduction**

The path of 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 meet your expectations. Caregiving can take a toll on your body, emotions, spirituality, and finances. Take care of yourself to cope with these changes. As frustrating as it is to hear that you need to do one more thing, it's the only way to sustain your role. By eating healthy, exercising, relaxing, getting enough sleep, and asking for help, you will have more energy to take care of your patient and can prevent health problems of your own.

The caregiver role may cause role shifts and tension within families and friendships. It helps to talk about these role shifts and expectations.

### **Suggestions to get started**

- Look at relaxation techniques and try them.
- Consider things that make you feel calm and renewed.
- Ask and accept help from other family members and friends.
- Develop a team of caregivers if possible.
- Ask for professional advice from your care team.
- Tell your care team, family, and friends what you need.
- Review the websites listed at the end of this guide for more information.
- As a caregiver, you may feel that you cannot share your frustrations or concerns with the patient. Find a person who you comfortable talking to and speak to them routinely.

## Keeping it real

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 (active, waiting for test results, etc.), causing a need for constant revision of my coping skills. At times, self-care may even 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 be required to act as a liaison between family members, co-workers, friends, etc. 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 and 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 Guiley cared for her husband during his treatment at SCCA. She is currently a stay-at-home mom with a smart and sassy six year old and a happy and energetic 1 year old. She is excited to be giving back to SCCA as a Patient and Family Advisor. She lives with her husband and kiddos in North Seattle. She shares her experience as a caregiver in hopes it will guide you as you take on this new role.*

## Tips from Someone Who Has Been There

**Tom Olsson** - Tom cared for his wife. He is currently on the SCCA Patient and Family Advisory committee.

- Even if you don't think you need help, you do.
- Don't feel guilty about doing something for yourself.
- Realize that other family members and friends react different ways. Some people may be quiet or distant, others supportive.
- Focus on having a goal, something in the future outside of cancer.
  - Family events
  - Picnics
  - Seeing a new movie
- You can pick up your own medications from the Pharmacy.
- Don't be afraid to ask questions—include questions to ask or “see questions in manual.”

# Establishing Your Role

## Caregiver Bill of Rights

I have the right to:

- Care for myself.
- Seek help from others.
- Express difficult feelings.
- Reject any attempt to cause guilt.
- Take pride in what I am doing.
- Protect my individuality.
- Maintain parts of my own life.
- Receive consideration, affection, forgiveness, and acceptance.

## Examples of Caregiver Responsibilities

Making Arrangements

- Transportation
- Financial
- Tracking appointments

Giving Emotional Support

- Being physically present
- Giving encouragement
- Assist with finding ways to cope

Providing Physical Care

- Identifying changes in patient's condition
- Obtaining medical care if needed
- Reporting symptoms to healthcare staff
- Monitoring self-administration of oral medications
- Recording medications taken/administered
- Acquiring and maintaining medical supplies
- Performing additional tasks, such as central line care

Maintaining the Home Environment

- Cleaning
- Cooking
- Grocery shopping

Patient Advocacy

- Gathering information and assuring that pertinent information is given to medical staff
- Helping with decision-making

Providing Assistance/Support to Others

- Serving as a communication link with other family members or friends

- Imparting information to children
- Providing child care

## **For the Caregiver: A New Role**

### **Navigating the Challenging Territory of Caregiving**

Being a caregiver is one of the most important and loving things you can do for someone. Since you're reading this, you're likely one of the millions of Americans who are taking on this role. Navigating this new terrain isn't without its challenges, but while everyone's cancer journey is unique, there are some caregiving tips that apply to nearly everyone.

- Talk it out. Generally speaking, cancer does not move at breakneck speed, and it's important to take some time to process what's happening. Talk to the patient 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 the doctor's OK, record the session. If you have permission to talk with the doctor yourself, you can; otherwise, let the patient lead the conversation. Once the treatment plan has been determined by the medical team, get the plan in writing. Ask questions about any points that are not clear.
- Be realistic about what's ahead. Treatment can be taxing, 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 toll chemo takes can be cumulative. The patient may feel fine at the outset of treatment but will likely feel worse before starting to feel better.
- Kind gestures help. Small gifts and cards can help lift your loved one's spirits. Experts say it's completely normal for patients to experience days when they feel, lonely, afraid, or depressed. Allowing the patient some time and space to be alone.
- Discuss legal and financial issues. If the patient hasn't already done so, he or she 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, CDs, and contact information for financial advisers.
- Allow the person to express feelings. As a caregiver, you want to be sure the patient feels safe and comfortable expressing exactly how he or she feels. You don't want the patient to feel the need to be upbeat all the time.
- Call a family meeting. Friends and family, regardless of distance, may want to be involved. Organize a family meeting, even by phone, to discuss who will do what. It's important for the patient to be involved, too. Quarterly or monthly follow-up meetings should be planned to allow for revisions to the caregiving plan.

Finally, if outside help is needed, be it a home health aide or hospice worker, be honest with the patient. Ultimately, patients should maintain as much independence as they can and, as much as possible, control decisions about their care.

*Cure Magazine. (March 26, 2013). Caregiving: Taking on a New Role. Retrieved from: [www.curetoday.com/index.cfm/fuseaction/article.show/id/2/article\\_id/1029](http://www.curetoday.com/index.cfm/fuseaction/article.show/id/2/article_id/1029)*

## **Suggestions for Coping with Care at Home**

- Ask questions of your doctor and nurse. If you are not sure have a question, use the important phone numbers provided and call.
- Remember that you are a member of the healthcare team and your input is important. Keep your nurse and doctor informed.
- Review the symptom sheets provided if the patient is experiencing any symptoms and call for help.
- Review hints for self-care.
- Ask your family/friends for help before you are too fatigued.
- Keep a list of what friends can do, and delegate tasks. For example, one person could drive you to an appointment, another could make a meal and another could go to the grocery store. Some people have more time than others, and but that is where a list would can be helpful.
- Organize your day into manageable segments.
- Develop a schedule each day/week with the family caregiver who is providing the care. This process allows family members or friends to be in agreement with the goals for the day or week. If everyone is working with the same agenda in mind, the tension within a family usually decreases.
- Remember the staff at the SCCA is here to support you as the patient and caregiver. Tell your doctor or nurse if you need more support. Call the social worker for additional emotional support.
- Visit these personal websites to keep family and friends informed:
  - [www.caringbridge.com](http://www.caringbridge.com)
  - [www.carepages.com](http://www.carepages.com)
- Use websites and apps to organize help from family and friends, such as:
  - [www.mealtrain.com](http://www.mealtrain.com)
  - [www.standwith.com](http://www.standwith.com)



## Patient/Caregiver Schedule Example

Time	Activity	Log of Issues/Symptoms
7:00 am		
8:00 am		
9:00 am		
10:00 am		
11:00 am		
12:00 pm		
1:00 pm		
2:00 pm		

## Medication Schedule Example

Medication	Purpose	Amount and Schedule	8-9am	12-1pm	4-5pm	8-9pm

## Taking Care of Yourself

### Taking Care of the Caregiver

Caregivers are encouraged to take care of themselves through exercise, proper diet, taking breaks, and adequate sleep. Caregivers can benefit by following these suggestions for self-care and caregiving.

Here are some helpful tips from Rosalynn Carter's book, *Helping Yourself to Help Others*:

- Listen to your friends. Be open to others' observations.
- Know your limits.
- Focus on your loved one's strengths.
- Learn relaxation techniques.
- Take care of your health.
- Maintain a life outside your caregiving role.
- Keep a daily "burnout log."
- Insist on private time.
- Build a caregiving team.
- Rely on your sense of humor.
- Appreciate the benefits of leisure time.
- Help your loved one find a support group.
- Seek professional help.
- Appreciate your own efforts.
- Seek spiritual renewal.
- Set a daily routine and schedule.
- Order groceries online.

### Self-Care: How are you doing?

I feel rested and calm.	T	F
I am getting enough sleep.	T	F
I have someone to talk to.	T	F
I am eating right.	T	F
I am exercising regularly.	T	F

If you answered more than two false, then read the Recipe for Support on the next page.

## Recipe for Support

- Stop in at the Patient and Family Services office on the 1<sup>st</sup> floor next to registration and ask to see a social worker or chaplain.
- Visit our Patient and Family Education Resource Center for Support Group information on the 3<sup>rd</sup> Floor of the clinic
- Attend a Yoga class.
- Go for a walk or exercise
- Plan time for leisure activities.
- Talk to someone you trust.
- Make a doctor's appointment for yourself.
- Treat yourself to something that makes you feel good.
- Keep a journal or express yourself through art.
- Join an online support group for caregivers.
- Call your nurse with any questions or concerns.
- 

## **Symptoms of Caregiver Burnout**

Being a caregiver is a rewarding, yet demanding job. Here are a few thoughts to keep in mind during the caregiver journey.

### **Signs of Burnout**

- Irritability
- Insomnia
- Physical complaints
- Fatigue
- Decreased motivation
- Anger
- Resentment
- Emotional exhaustion

### **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
- Difficulty delegating
- Perfectionism
- Being a "giver" rather than "receiver"

### **Steps to Getting Help**

- Recognize that not all tasks are of the same importance
- List all tasks that need to get done
- Group your list into categories
- Review your list of tasks with the intent of sorting
- Write down your worries
- Know what you can and cannot control
- Pat yourself on the back
- Asking for help is not a weakness—Ask someone to help

### **Time for You: Relaxation Techniques**

#### **Deep Breath/Tense, Exhale/Relax, Yawn**

1. Clench your fists; breathe in deeply and hold it a moment.
2. Breathe out slowly and go limp as a rag doll.
3. Start yawning.

Additional points: Yawning becomes spontaneous. It is also contagious, so others may begin yawning and relaxing too.

#### **Heartbeat Breathing For Relaxation**

Before you do this, if you are unsure about how to find and count your pulse rate (usually radial pulse at the wrist), ask your nurse to help you.

1. Take a deep, comfortable breath.
2. Close your eyes or focus on your hands.
3. Count your radial pulse (at the wrist) for two beats.
4. Inhale while you count the next two beats.
5. Exhale while you count the next three beats.
6. Inhale and exhale in this manner several times.

Additional points: You can do this quickly if you are suddenly anxious or fearful. You can do this without drawing attention to yourself. The pulse (heart) rate usually slows noticeably.

#### **Humor for Relaxation**

Laugh when you hurt? Hurting is rarely funny, but people who hurt sometimes find that occasional humor is one of the most effective ways to deal with pain. Why not try some of the following?

1. Watch television programs that are really funny to you.
2. Listen to recordings by comedians that you find hysterical.
3. Read books that make you laugh.

Something funny can certainly be distracting, but its value seems to go beyond a momentary redirection of thoughts. Humor may produce relaxation. For example, when you laugh, it is almost impossible to maintain muscle contraction. A simple example of this is when two or more people attempt to lift a heavy object in unison. One of them may be in charge of

coordinating the efforts. That person counts or gives some cue to signal everyone to lift at the same time. But if they laugh, they fail. The result is familiar: the lifters become limp, drop the object, and sometimes actually fall to the floor. Laughter causes skeletal muscle relaxation; the skeletal muscles become too limp to hold or lift an object. When Norman Cousins reported on his painful illness, he noted that 10 minutes of belly laughter resulted in 2 hours of sound sleep. Many have speculated about the reason. Could laughing have relaxed him?

**Patient/Family Teaching Point: Jaw Relaxation**

1. Let your lower jaw drop slightly, as though you were starting a small yawn.
2. Keep your tongue quiet and resting in the bottom of your mouth.
3. Let your lips get soft.
4. Breathe slowly, evenly, and rhythmically: inhale, exhale, rest.
5. Allow yourself to stop forming words with your lips and stop thinking words.

**Additional points:** This technique may reduce both pain and distress, especially postoperatively.

**Progressive Muscle Relaxation**

Progressive Muscle Relaxation is a great way to reduce overall body tension. This is an easy exercise. All you need is a few minutes, a private spot, and a comfortable position either lying down or sitting up.

1. Start by tensing all the muscles in your face. Close your eyes as tightly as possible, clench your teeth, pucker your lips, move your ears. Inhale and count to five or eight as you hold the tensed facial position.
2. Exhale and relax completely—blow out all your stress. Relax and repeat. Allow the muscles you just used to completely relax. Feel the stress melt away, enjoy the feeling.
3. Next, completely tense your neck and shoulders, shrug your shoulders, inhaling and counting to either five or eight. Then exhale, relax, and repeat.

Continue down your body, repeating the procedure with the following muscle groups:

- Chest
- Abdomen
- Entire right arm and left arm (forearm and hand)
- Buttocks
- Right leg and left leg (thighs, calves and foot)

A shortened version includes tensing the four main muscle groups:

- Face
- Neck, shoulders and arms
- Abdomen and chest
- Buttocks, legs, and feet

By focusing on each muscle group one after the other, you can relax your body in a matter of minutes.

*May be duplicated for use in clinical practice. Adapted from McCaffery, M. and Beebe, A:  
PAIN: CLINICAL MANUAL FOR NURSING PRACTICE, St. Louis, 1989, The CV Mosby Company.*

# Tools You Can Use

## 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 the SCCA. 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 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	<i>North Seattle: 206-368-7667</i> <i>South Seattle: 206-329-4695</i>
Right At Home	206-774-1100
Synergy HomeCare	206-420-4934
Visiting Angels	1-800-365-4189

### **Suggestions for 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?

## Safe Lifting

Back injuries can easily happen when lifting improperly. Before trying to lift, it is important that you make sure you are keeping yourself safe and not lifting more than you can handle. You should never try to lift something too heavy for you. Remember that it is always better to get assistance. If you are having difficulty assisting your loved one in this way, please discuss with your healthcare provider.

### **What are some simple ways to keep safe?**

- 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.
- Ask for help: Always get help if you need it and use lift devices whenever they are available.

The SCCA Physical Therapy Department is available to teach you how to lift and the proper body mechanics to keep you and your patient safe. Ask your nurse or doctor for a referral. You may also visit the website listed below; it shows you how to move a patient from a sitting position, how to sit down, and stand up.

*Information adapted from: [www.orthoinfo.aaos.org/topic.cfm?topic=A00096](http://www.orthoinfo.aaos.org/topic.cfm?topic=A00096)*

## **For the Caregiver: Taking Care of Yourself**

**Reach out.** 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 chat groups, and support organizations to help reduce feelings of isolation.

Support groups for cancer patients and caregivers can be located through local hospitals or the American Cancer Society. It makes a huge difference to know you're not the only one having these feelings. Try exercise, meditation, and other stress reduction techniques, too. If nothing seems to help, it may be time to consult a therapist or doctor.



**Accept help.** If friends or neighbors ask what they can do to help, tell them. Veteran caregivers suggest keeping a list in your pocket. That way, you can pull it out and let them know exactly what you need. If friends or relatives are not available to step in for a few hours, hire someone or find adult day care. The U.S. Administration on Aging offers a national database of elder care providers at [eldercare.gov](http://eldercare.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.

**Keep up your health.** With everything they have to do in a day, caregivers often neglect basic health maintenance. Some simple things to keep in mind 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). Line up help 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 learn from it, you may have less depression and anxiety. Caregiving can help you find more meaning in your life and focus on your highest priorities. Work on your personal growth. Participate in an art therapy workshop, begin a journal, talk with a counselor, or lean on your faith community.

*Cure Magazine (March 5, 2009). Caregiving: Practicing Self Care. Retrieved from: [http://curetoday.com/index.cfm/fuseaction/journey.showArticle/id/9/enableStageSubMenu/7/article\\_id/1031](http://curetoday.com/index.cfm/fuseaction/journey.showArticle/id/9/enableStageSubMenu/7/article_id/1031)*

## How to Build Emotional Resilience

Emotional resilience is a trait you can develop as you cope with cancer. What are the traits of emotional resilience?

- Emotional awareness
- Perseverance
- Internal sense of control
- Support
- Humor
- Perspective

**Make connections.** Good relationships with close family members, friends or others are important. Accepting help and support from those who care about you and will listen to you strengthens resilience. Some people find that being active in civic groups, faith-based

organizations, or other local groups provides social support and can help with reclaiming hope. Assisting others in their time of need can also benefit the helper.

**Avoid seeing crises as insurmountable problems.** 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 attainable as a result of adverse situations. Accepting circumstances that cannot be changed can help you focus on circumstances that you can alter.

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

**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 that will happen in your life. Instead of worrying about what you fear, visualize what you want and hope for.

## **Helping Children Cope When Someone They Love Has Cancer**

## **Important Common Concerns and Fears**

Even if the child does not ask these questions, they may wonder:

### **Will I get cancer?**

Cancer is not contagious. You cannot “catch” cancer.

### **Did something I do cause the illness?**

No. Cancer can just happen. Scientists are doing research to understand this better, but we know nothing you (the child) 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 do not stop. This makes the body not work right. Chemotherapy kills these fast growing cells. During surgery, the doctor takes out the group of cancer cells (tumor). 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.”

Depending on the child’s age and his/her experience with cancer, he or she may wonder:

### **Are you (or my loved one) going to die from cancer?**

Your answer to this question will change based on the 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 (the loved one) to get well. I will let you know if this changes or if I am worried about (the loved one) dying. I also want you to tell me when you are worried. What would you worry about most if (the loved one) died?” A child may have specific fears that he or she wants to talk about (“Where would my room be? Who would watch me after school?”).

### **Suggestions for Communication: When and How Much?**

You know best. How you talk 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; stay with the facts.

First, learn what you can about the illness, including side effects and the schedule of treatment, so that you are able to prepare your child and answer questions about what to expect.

Choose a time to talk when you feel you can calmly discuss the illness and support your child with his/her emotional reaction. Your child may be upset by the information or he/she may have very little reaction. Children often need to absorb this information over time.

Children can usually sense when something is wrong and often imagine the worst if they do not know what is happening. Teaching children early about the diagnosis helps them feel included and helps them understand the changes they see.

Invite a professional or a close family member to help prepare you mentally and emotionally. 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. Begin with what the child sees and knows: "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 the 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 language they can understand (see Age Considerations section) 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.

Children will vary in how much information they want to have and can cope with; the goal is to give enough information that will address their fears and give them a sense of security in the midst of the upcoming changes. Allow them to guide you with how they are feeling.

Be truthful about things you cannot answer. Sometimes an assurance that everything will work out well is not possible. Assure them that they will be taken care of no matter what, and 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.

Try to help your child draw out his/her feelings (e.g., adult says, "When I feel sad I...", then asks child to draw picture of that emotion and talk about a time when they felt that emotion).

If it's a parent that's ill, give the children tasks to help that parent (making them a picture, etc.); making "books" for younger siblings about illness, journaling and scrapbooking about the experience, talking about the best and worst parts of each day, and asking how/if they would like to help the family are tasks children can do.

### **Meeting Your Child's Needs**

It is extremely challenging to parent and to manage cancer treatment and side effects. First and foremost, take care of yourself:

- Recognize your limits and adjust expectations of yourself.
- Set aside time every day for yourself.
- Eat healthy foods.
- Maintain physical activity and get enough sleep.
- Allow people to help, and have a list handy of specific things others can do.
- Utilize friends, family members, support groups, and professionals for emotional support.

### **Children's emotional needs:**

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 there before the visit.
- Your child will cope with this in his or her 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, talking with the loved one about the best and worst of his or her day, filling the loved one's water pitcher each morning, etc.
- Maintain fun family times as possible. Make special adapted plans for holidays or events.
- Discuss changes in routine and what the child can expect.
- Let others help to fill in gaps, such as a trusted uncle or aunt taking your child to a game.
- Invite fun, imagination, and interactive play into everyday activities. For example, an in home "picnic" at meal time, comedy movies at night, or a new craft for family members to work on together.

### **Social and Developmental needs:**

- Help maintain as much contact as they can with friends, family, and others they care about (in person, writing, phone, email).
- 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, what is and what is not okay to talk about outside of the family.
- It is normal for the 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. Rules may need some flexibility during stressful periods (e.g. bedtime). Discuss any changes with your child.
- Involve all caretakers to maintain as much consistency in the child's care and discipline plan as possible (e.g. Grandma's rules similar to Mom's).

### **Age Considerations**

#### Preschool Age Children (approx. 3-5 years old):

- Tend to be egocentric; believe that the world revolves around them and care mostly about how the illness affects them.
- Inclined to have magical thoughts; think they have the power and ability to control things (e.g. think they can cause someone's illness by having bad thoughts about that person or by misbehaving).
- 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 (e.g. will act out more for attention) or acting younger in terms of development (e.g. bedwetting, clinginess).
- Are good at expressing feelings/emotions through play and sometimes need help identifying feelings.
- Often believe that death is reversible and that a person who has died will/can come back.

#### School Age Children (approx. 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 (e.g. side-effects, physical changes).
- May react by being sad, mad, and/or irritable; have physical complaints or headache, stomachache, etc.; may be angry towards the sick loved one; have poor concentration; or have difficulty adapting to changes in routine.

#### Teenagers (12 years old and above):

- Adolescents 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 siblings.
- May react with anger, rebellion, depression and anxiety, withdrawal, physical symptoms such as stomachaches and headaches, and keeping feelings to themselves.

### References for More Information

A helpful Guide for Family Caregivers in Cancer from the National Cancer Institute can be found at [www.cancer.gov/cancertopics/pdq/supportivecare/caregivers/patient](http://www.cancer.gov/cancertopics/pdq/supportivecare/caregivers/patient). This document reviews assessment of caregiver needs and resources for caregivers.

- 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.
- Helping Children When a Family Member Has Cancer: Dealing With Diagnosis," the American Cancer Society, [www.cancer.org](http://www.cancer.org)
- "Helping Children When a Family Member Has Cancer: Dealing With Recurrence or Progressive Illness," the American Cancer Society, [www.cancer.org](http://www.cancer.org)
- Art with Heart (Seattle-based group that uses art therapy to help kids deal with crisis), [www.artwithheart.org](http://www.artwithheart.org)

### Other Recommended Readings

For the parent:

- How to Help Children Through a Parent's Serious Illness, by Kathleen McCue, with Ron Bonn
- Can I Still Kiss You? Answering Your Children's Questions About Cancer, by Neil Russell
- When a Parent Has Cancer: A Guide to Caring for Your Children, by Wendy S. Harpham

For the child (to read with the adult):

- When Someone You Love Is Being Treated For Cancer, by the National Cancer Institute
- 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
- Sammy's Mommy Has Cancer, by Sherry Kohlenberg, Lauri Crow (Illustrator)
- The Year My Mother Was Bald, by Ann Speltz, Kate Sternberg (Illustrator)
- Because Someone I Love Has Cancer: Kids' Activity Book, by American Cancer Society
- Life Isn't Always a Day at the Beach: A Book for All Children Whose Lives Are Affected by Cancer, by Pam Ganz
- When Someone Has a Very Serious Illness: Children Can Learn to Cope with Loss and Change, by Marge Heegaa
- Vanishing Cookies: Doing Ok When a Parent Has Cancer, by Michelle B. Goodman

### Questions?

How to contact us:

- Seattle Cancer Care Alliance: (206) 288-1000
- Patient and Family Services: (206) 288-1076
- Patient and Family Education Resource Center: (206) 288-2081
- Child Life Specialist: (206) 288-7621



## Documents Needed for Family Medical Leave Act (FMLA) and Disability

1. Obtain any forms needed for medical leave from your employer or the employer of your caregiver. This may require a discussion with a Human Resource Department to provide you with the necessary forms.
2. Make sure the patient or caregiver portion of the form(s) are filled out before bringing/sending them in.
3. Bring any disability, FMLA, 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 nurse office at \_\_\_\_\_ at least one week prior to when the paperwork is due.
  - a. You will be contacted if a phone consult or visit is needed.
5. Confirm the contact information for you or your caregiver's employer below.
6. Please allow 1 week for completion of this process. We will fax your completed paperwork to your employer. We will mail you a copy.

Please fill out this bottom section and attach to FMLA/Disability paperwork.

Today's Date: \_\_\_\_\_

Name of patient: \_\_\_\_\_

Physician Treating Patient: \_\_\_\_\_ U#: \_\_\_\_\_

Name of caregiver: \_\_\_\_\_

(if forms are for someone other than patient)

Date forms needed by: \_\_\_\_\_

Employer: \_\_\_\_\_

Main Employer Contact: \_\_\_\_\_

Employer's Mailing Address: \_\_\_\_\_

Employer Contact Telephone #: \_\_\_\_\_

Employer Contact Fax #: \_\_\_\_\_

Employee reference or case # (if known): \_\_\_\_\_

Please Confirm Your Mailing Address:

\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

## Websites and Resources

We recommend a few helpful sites to visit that are full of information to help you on your journey.

### **National Cancer Institute**

1-800-4-CANCER (422-6237)

<http://www.cancer.gov>

### **National Cancer Institute Publications**

Many of these publications are also available at the Patient and Family Education Resource Center on the third floor of the Clinic.

### **Facing Forward - Life After Cancer Treatment**

[www.cancer.gov/cancertopics/coping/life-after-treatment](http://www.cancer.gov/cancertopics/coping/life-after-treatment)

### **When Someone You Love is Being Treated for Cancer**

[www.cancer.gov/cancertopics/coping/when-someone-you-love-is-treated](http://www.cancer.gov/cancertopics/coping/when-someone-you-love-is-treated)

### **Taking Time: Support for People with Cancer**

<http://www.cancer.gov/cancertopics/takingtime>

### **National Institute on Aging**

So Far Away - Twenty Questions and Answers about Long-Distance Caregiving

[www.nia.nih.gov/health/publication/so-far-away-twenty-questions-and-answers-about-long-distance-caregiving](http://www.nia.nih.gov/health/publication/so-far-away-twenty-questions-and-answers-about-long-distance-caregiving)

### **Guide for Family Caregivers in Cancer**

<http://www.cancer.gov/about-cancer/coping/family-friends/family-caregivers-pdq>

### **Caring for the Caregiver**

[www.cancer.gov/cancertopics/coping/caring-for-the-caregiver](http://www.cancer.gov/cancertopics/coping/caring-for-the-caregiver)

### **When Someone You Love is Being Treated for Cancer**

[www.cancer.gov/cancertopics/cancerlibrary/ebooks/when-someone-you-love-is-being-treated](http://www.cancer.gov/cancertopics/cancerlibrary/ebooks/when-someone-you-love-is-being-treated)

### **Employment Rights Cancer and the Americans with Disabilities Act**

[www.eeoc.gov/laws/types/cancer.cfm](http://www.eeoc.gov/laws/types/cancer.cfm)

### **The Job Accommodation Network**

<http://askjan.org>

### **UW Medicine Virtual Clinic**

<https://virtualclinic.uwmedicine.org/#/home>

1-855-520-5250

# Caregiver Organizations, Apps, and Websites

Caregiver.com

[www.caregiver.com](http://www.caregiver.com)

Family Caregiver Alliance

[www.caregiver.org](http://www.caregiver.org)

Lotsa Helping Hands

[www.lotsahelpinghands.com](http://www.lotsahelpinghands.com)

Well Spouse Foundation

[www.wellspouse.org](http://www.wellspouse.org)

Personal Websites to Communicate with Friends and Family

[www.caringbridge.org/](http://www.caringbridge.org/)

[www.carepages.com/](http://www.carepages.com/)

Organizing Help from Family and Friends

[www.mealtrain.com](http://www.mealtrain.com)

<http://www.standwith.com>

## Apps

My Pillbox: Search in your App Store for “My Pillbox”

Carezone: Search in your App store for “CareZone” or go to <https://carezone.com>