#### Visit www.LLS.org/FamilyWorkbook to access all chapters and worksheets.

As a parent, especially as the parent of a child who has cancer, you may neglect to take good care of your own needs. In addition to caring for your sick child, you likely have other responsibilities such as caring for the rest of your family, managing a relationship with your spouse or partner, and/or working a job. All of this can be overwhelming. Quite likely, taking care of your personal needs has been a very low priority. You may even feel guilty if you do take time for yourself. You may feel depressed. However, to offer your child the best possible care, you need to be healthy and well yourself, both physically and emotionally.

Figuring out strategies to add self-care to your day or week can help. The first step is to adjust your mindset. You can make small changes to your daily routines now. When you are comfortable with those, you can incorporate more changes, over time, to maintain your own well-being. Time spent caring for yourself is time well spent.

Ways to Care Yourself. Caring for a sick child and worrying about what the future holds is exhausting. Take a moment to reflect on what is working and what is not working for you in your daily and weekly routines.

**Make Changes for Your Health.** The list below offers ways to care for yourself. To start, pick one or two of the suggestions to fit into your schedule and see if they work for you. If you find that something is adding more stress to your day, try a different approach. Even if you only have a few minutes to spare here and there, taking that time for yourself and doing some of these things can still make a difference.

- Get some form of exercise such as walking or taking a class.
- Create a support system. Call friends or a family member when you need to talk or need help.
- Keep up with a hobby or make time for something you enjoy doing, such as reading, painting or playing games.
- Try to stay connected with friends, even if you have had to cut back on your social life.
- Try journaling to provide an outlet to express yourself so that you can process and cope with your emotions.
- Eat well-balanced meals. Caregiving can leave little time for meal preparation, and many people turn to fast food or junk food. Get the nutrition your body needs.
- Have a place where you can go to "escape" and just be by yourself.
- Set priorities each day and make sure the most important tasks get done, but try not to worry about items further down on your to-do list.
- Seek proper medical care for yourself as well by seeing your primary care provider (PCP). Follow any directions given by your PCP. For example, take any medications as prescribed.
- Try to cut out smoking and drinking alcohol.

## TIP:

In order to care for your family, you have to take care of yourself too. Your co-parent may also be struggling to prioritize selfcare. Share this information with them too. As the saying goes: You can't pour from an empty cup.



# **12** CARING FOR YOURSELF

- Try to get a good amount of sleep each night and find time to rest throughout the day.
- Create a self-care plan and set small goals to improve your well-being. See *Creating a Self-care Plan* below.

**Accept Help From Friends and Family Members.** Learning to let go and to accept help will lower your anxiety levels and raise your spirits. People want to chip in, but they may not be sure what kinds of help you need. Keep a list of tasks. That way, when friends or family members offer to help, you can give them specific tasks. See **Ask for Help and Delegate Tasks** on page 5. Try using a caregiver mobile app to help you coordinate help from family and friends.

- Examples of caregiving coordination apps include
  - Lotsa Helping Hands: www.lotsahelpinghands.com
  - Caringbridge: www.caringbridge.org
  - MyLifeLine: www.mylifeline.org

**Take a Break.** As a parent, you can't always take a day off, but learning techniques to alleviate stress throughout the day can be extremely helpful. Try deep-breathing techniques. Listen to relaxing music, take a short walk or call a friend. However you choose to get away during the day, you need at least 30 minutes a day to yourself. The 30 minutes does not need to be all at one time. You could also take two 15-minute breaks or three 10-minute breaks. Breaks should be at least 10 minutes.



For more information about coping strategies, visit **www.LLS.org/booklets** to view *Managing Stress: How stress affects you and ways to cope.* 

### Creating a Self-care Plan. Self-care is:

- Taking action to maintain or improve your own mental, emotional and physical health, especially during times of stress
- Intentionally doing things that improve your mood and lower your stress levels

Use the following prompts to create a self-care plan. You may know you want to take time for yourself, but it can often be hard to actually find the time to do it unless you consciously make time or set self-care goals. You may not always be able to stick to your plan—don't be discouraged. You can always revisit and modify your self-care goals. **Self-care should help you feel better, not be an additional source of stress**.

Physical Self-care Plan. As a caregiver, if you are not physically well, you will not be able to take care of your family.

Check all the statements below that are true.

- I eat a well-balanced diet that includes a variety of fruits and vegetables, proteins, whole grains and healthy fats.
  - I drink at least eight 8-oz glasses of water or fluid a day (an "8×8" goal).
- I sleep well each night and wake up feeling rested.
- I exercise for 30 minutes at least three times a week.
- I do not smoke or use tobacco.
- I only drink alcohol in moderation.
- I keep up with my own medical needs, such as getting an annual checkup from my primary care provider, and I get regular dental cleanings.

Did you leave any of these statements unchecked? If so, you may need to consider improving those aspects of physical self-care. Talk to your primary care provider about ways to improve your health and well-being.

What are some ways in which you can improve your physical well-being?

Example: Drink more water to stay hydrated.

#### Write down a few short-term goals to improve your physical well-being.

Example: I will keep a water bottle with me throughout the day to make sure I meet the "8x8" goal.

**Mental and Emotional Self-care Plan.** Taking care of your mental and emotional health is just as important as caring for your physical health. It's important to take time for yourself each day and to keep up with activities that you enjoy. With the daily responsibilities of caregiving, you may forget to do these things. Make a conscious effort to take time to care for your mental and emotional health.

What activities do you enjoy? Check all that apply.

	Listening to music, playing an instrument or singing
	Reading or listening to audiobooks
	Exercising or participating in group exercise classes
	Playing sports or organized games with friends
	Hiking, fishing or other outdoor sports
	Meditating or practicing yoga
	Painting, drawing or other types of art making
	Journaling or creative writing
	Attending religious or spiritual services
	Activities with friends or family
	Practicing personal care, such as long baths, manicures or face masks
	Cooking or baking
	Watching movies or TV shows
	Playing video or computer games
	Puzzles
	Yard work or gardening

- Other: \_\_\_\_\_
- Other:\_\_\_\_\_

Any of these activities can be part of a self-care plan. Pick one or two of your favorite activities and make them a priority in your day-to-day life. Then fill out the following statements to create goals for emotional self-care.

I will set aside time to \_\_\_\_\_\_ once a day.

Examples: Drink coffee on the front porch, read a devotional, meditate and stretch, write in a journal.

I will set aside time to\_\_\_\_\_\_ once a week.

Examples: Get dinner with friends, attend a religious or spiritual service, go to an art or exercise class.

Change the activity and frequency to adjust to your lifestyle and needs, but do be sure to make the time for yourself.

Stay Calm Strategy. When caring for a child who has cancer, there will be times that are difficult and emotional. It's unavoidable. Prepare for these moments by having a strategy in place to help **Deep-Belly-Breathing Exercise** yourself calm down if you feel anxious or overwhelmed. Having a plan in place, in advance, will help you better manage unexpected 1. Sit in a comfortable position and intense emotions. close your eyes. Try the following strategies: 2. Place one hand on your stomach and your other hand on your chest. Do a breathing exercise. 3. Take a deep breath through your Repeat a meaningful mantra, affirmation or prayer. nose. The hand on your stomach should rise. The hand on your chest Close your eyes and sit in silence. should not move much. Stand up and stretch. 4. Exhale through your nose. The Take a quick walk outside. hand on your stomach should move, and the hand on your chest Call a close friend or family member. should not move much. Focus on your breathing and your hands. When I feel overwhelmed I will You can find a variety of breathing exercises online. Try a few different ones until you find one that works for you.

City of Hope offers videos with more breathing and meditation exercises on their YouTube channel. You can visit this channel at **www.youtube.com/user/cityofhopeonline** and go to the playlists tab to access the "Living Well" playlist with breathing and mediation exercises. **Ask for Help and Delegate Tasks.** As a parent, you may feel that you need to take on every aspect of your child's care alone, but this isn't the case. Even getting help with the smallest of tasks can lessen the load. More than likely, there are friends and family members who really want to help—they just may not know how, so let them know!

What tasks could you delegate to someone else? Use the chart below to write down tasks when you think of them and some friends and family members who can help you with your caregiver responsibilities.

TASK	HELPER	NOTES
Example: Take John to appointment on Monday	Aunt Susan	Susan doesn't work on Mondays and she lives close by.

Use **Worksheet 21: Creating a Self-care Plan** if you need to modify your self-care plan or if you would like an additional copy.

**Resources and Support Programs.** Caring for a sick child can be a lonely experience. Parents often don't feel that they should be seeking support for themselves. But to be able to care for children, it is very important that parents take really good care of themselves, too. There are several ways to reach out to other people who are in similar situations or have recently been through similar experiences. You can reach out to members of the healthcare team for local suggestions. Many hospitals and treatment centers host support groups.

The Leukemia & Lymphoma Society (LLS) offers a number of helpful resources. For more information about any of the services listed below, visit **www.LLS.org** or contact an LLS Information Specialist at **(800) 955-4572**.

- Weekly Online Chat for Caregivers: Our live, weekly online chat provides a friendly forum where you can share your experiences and chat with other caregivers and parents. Each chat is moderated by an oncology social worker. Visit www.LLS.org/chat to learn more.
- The Patti Robinson Kaufmann First Connection® Program: First Connection is a telephone support program that links you with a trained peer volunteer who has experienced a similar situation or who is a childhood cancer survivor. Visit www.LLS.org/FirstConnection to learn more.
- LLS Community: Chat with other caregivers and parents and stay up-to-date on the latest diagnosis and treatment news. Share your experiences and get personalized support from trained LLS staff. Visit www.LLS.org/community to sign up.
- The Family Support Groups Program: The Leukemia & Lymphoma Society (LLS) Family Support Groups are open to patients, parents, family members and caregivers. Volunteer nurses, social workers and other healthcare professionals lead the groups. Contact an LLS Information Specialist at (800) 955-4572 for more information.

**Caregivers and Depression.** Feeling sad, depressed, or anxious after your child is diagnosed with cancer is normal. However, if these feelings start to interfere with your daily activities, you may need individual counseling from a medical professional.

Symptoms and/or signs of clinical depression include:

- Ongoing sadness or feelings of hopelessness
- Loss of interest or pleasure in most activities
- Major weight loss or weight gain
- Agitation or restlessness
- Fatigue or no energy
- Trouble sleeping
- Trouble focusing, remembering, or making decisions
- Feeling worthless, guilty, or helpless
- Thoughts of death or suicide

Don't be afraid to seek help. For a referral to a mental health professional, reach out to the members of the healthcare team, visit your own doctor or call your insurance provider for recommendations.

"And then I just found a couple of moms, not online, but who live in my community, who have gone through or are on the same journey and so that's been probably one of the biggest sources of support."

—Parent of child with cancer in response to LLS Caregiver Survey 2019

## Caring for Yourself Notes
