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INTRODUCTION



When Your Child Has Cancer. Hearing that your child has cancer is terrifying. Today, however, most childhood blood cancer patients can expect to have full and productive lives. Thanks to new and improved therapies, survival rates for childhood blood cancer have improved significantly over the past several decades. Researchers continue to develop new treatments to improve outcomes and decrease side effects.

Caring for a child who has cancer means you will have to find ways to navigate the complexities of treatment and follow-up care. Information, tips and resources that can help you are provided in this workbook.

What Does Caregiving Look Like? As a parent, you already provide for your child in many ways, but caring for a child with cancer brings new challenges. You will be spending a lot of time with your child at medical appointments and working closely with the members of your child's healthcare team to ensure your child is getting the best possible care. Depending on the treatment plan, your child may need to stay at the hospital overnight (or even for weeks) to receive treatment. You may have to deal with an emergency situation, such as a medical crisis requiring a trip to the emergency room. After your child's cancer treatment is completed, you will need to be vigilant about follow-up care and watch for long-term and late effects of treatment. You will also have to help your child when he or she returns to school.



Use **Worksheet 1: Emergency Room (ER) Plan** on and **Worksheet 2: Weather Emergency Plan** to prepare for an emergency situation.

In addition to caring for a child who has cancer, you may have other children, as well as other family members, who need your time and support too. Equally important, you need to look after yourself during this difficult time.

Caregiving Strategies. Sometimes you may feel overwhelmed, but the following suggestions can help you to be at your best to help your child:

- Ask for help and accept help. If you have a co-parent, work together to tackle these new responsibilities. Reach out to family members and friends for help with daily tasks. Some people will want to do everything, but others may wait to be asked and perhaps may need to be assigned a specific task. Most likely, your friends and family members do want to help, but they may not know how to unless you tell them. Talk to members of your child's healthcare team about difficulties you encounter—there may be resources available to help you. Remember, you are not alone.
- Learn as much as you can about caring for a child who has cancer. Members of the healthcare team will be able to tell you where you can find trusted information on your child's diagnosis and treatment plan. (Be wary of information you find online. Verify that it is from a reliable source.)

TIP:

The most important aspect of caregiving is learning to ask for help when needed and to accept help when offered.



For help finding information, contact an LLS Information Specialist at **(800) 955-4572** or visit www.LLS.org/InformationSpecialists for up-to-date disease and treatment information.

- Take care of yourself. Take time for yourself and address your own physical and emotional needs. Enlist the help of friends and family members to make sure you can have this time. You can better care for your child and your family if you are healthy and well.
- Give yourself a break. When you are caring for an ill child, there may be times when you start to resent your caregiving responsibilities. These thoughts may be followed by feelings of guilt. These feelings are normal and common. Parenting, especially caring for a child with cancer, is a difficult job so don't beat yourself up.
- Use a caregiver app to coordinate care. A caregiver mobile or web-based app helps you coordinate aspects of your child's care by organizing friends and family members who want to help. Use these apps to plan meal deliveries, set up rides to treatment, ask for volunteers who will do chores, find babysitters for your other children or give updates on your child and family's well-being. Apps also provide space for friends and family members to post messages of support. Use the "private" setting so only people you allow can view the information.



Examples of caregiving coordination apps include

- Lotsa Helping Hands: www.lotsahelpinghands.com
- Caringbridge: www.caringbridge.org
- MyLifeLine: www.mylifeline.org

Managing Your Emotions. You are likely to experience a wide range of emotions from the time your child is diagnosed with cancer, as well as during and after treatment. These emotions may include shock, denial, fear, anger, guilt, sadness or doubts about religious and spiritual beliefs. You may feel that life for your child and family will never be the same. Allow yourself to feel sad. Understand that you are not to blame for your child's diagnosis.

Over time, you'll find ways to adapt and gradually develop a new sense of normalcy for you and your family. All of these feelings are to be expected. But, if you feel consumed by feelings or are unable to function, seek professional help. Psychologists, social workers and spiritual advisers may also help you come to terms with your child's diagnosis. It's important to work through your feelings so you can help your child to cope and you can continue to manage other aspects of family life and work.



Many organizations help with cancer-related issues, such as financial assistance, support and counseling, assistance with transportation, etc. Don't be afraid to reach out to these organizations for support. To explore specific organizations by need, visit www.LLS.org/ResourceDirectory or call The Leukemia & Lymphoma Society (LLS) to speak with an Information Specialist at **(800) 955-4572**.
