

Coping with Childhood **Leukemia** and **Lymphoma**



A Message From John Walter

President and CEO of The Leukemia & Lymphoma Society

The Leukemia & Lymphoma Society (LLS) is committed to bringing you and your family the most up-to-date blood cancer information. We know how important it is for you to have an accurate understanding of your child's diagnosis, treatment and support options. With this knowledge, you and your child can work with members of the oncology team to move forward with the hope of remission and recovery. Cancer survival rates for children have improved dramatically during the last several decades. Our vision is that one day the great majority of people of all ages who have been diagnosed with blood cancers will be cured or will be able to manage their disease with a good quality of life. We hope that the information in this booklet will help you and your child along your journey.

LLS is the world's largest voluntary health organization dedicated to funding blood cancer research, education and patient services. Since the first funding in 1954, LLS has invested more than \$814 million in research specifically targeting blood cancers. We will continue to invest in research for cures and in programs and services that improve the quality of life of people who have blood cancers and their families.

We wish you well.

A handwritten signature in black ink, appearing to read "J. Walter". The signature is fluid and cursive, with a large loop at the beginning.

John Walter

President and CEO

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Introduction

Families face uncertainty when they are told that their child has leukemia, lymphoma or another type of cancer. It is a time filled with new people and situations, worries and change. It may help to learn that cancer survival rates for children have improved significantly during the last several decades. Doctors, nurses and scientists are working together around the world to continue to improve outcomes for children diagnosed with pediatric cancers – researchers continue to search for the causes, develop better treatments and decrease long-term effects. Social workers, psychologists, psychiatrists and other health professionals are also working to understand how to help children and families manage cancer and its treatment and maintain a good quality of life throughout survivorship.

Children with leukemia or lymphoma may face long periods of treatment. However, most can expect to have full and productive lives. Many childhood cancer survivors return to school, attend college, enter the workforce, marry and become parents. Still, each family living with a childhood cancer diagnosis is thrown into an unfamiliar world. *Coping With Childhood Leukemia and Lymphoma* is for families who are dealing with this difficult circumstance. We hope this information will help families to cope with the emotional and social aspects of their child's illness.

Here to Help

This booklet will help you talk to your child's doctor and treatment team about your fears and concerns. These actions will give members of your healthcare team the opportunity to answer your questions, extend emotional support and provide any needed referrals.

LLS Has Ways to Help. Treatment for blood cancers will affect your daily life, at least for a time. You may have questions about your child's treatment and want to have friends, family members or caregivers help you get information.

Making treatment choices, paying for medical care, communicating with healthcare providers, family members and friends—these are some of the stressors that go along with a cancer diagnosis. LLS offers free information and patient services for individuals and families touched by blood cancers.

Speak to an Information Specialist. Information Specialists are master's level oncology professionals. They provide accurate up-to-date disease and treatment information and are available to speak with callers Monday through Friday, 9 a.m. to 6 p.m. ET at (800) 955-4572. You can email infocenter@LLS.org or chat live with a Specialist at www.LLS.org.

Clinical Trials. Our Information Specialists help patients and caregivers work with their doctors to find out about specific clinical trials. Information Specialists conduct clinical-trial searches for patients, family members and healthcare professionals. You can also use TrialCheck®, an online clinical-trial search service supported by LLS that offers patients and caregivers immediate access to listings of blood cancer clinical trials. Please visit www.LLS.org/clinicaltrials.

Language Services. Free language services are available when you speak with an Information Specialist. Let your doctor know if you want a professional healthcare interpreter who speaks you and/or your child's native language or uses sign language to be present during your visit. Many times, this is a free service.

Free Materials. LLS publishes many free education and support materials for children, their families and healthcare professionals. PDF files can be either read online or downloaded. Free print versions can be ordered. Visit www.LLS.org/resourcecenter.

Información en Español. LLS has a number of resources available in Spanish for patients, caregivers and healthcare professionals. You can read and download these resources online at www.LLS.org/espanol or order printed copies by mail or phone.

Other Helpful Organizations. Our website, www.LLS.org/resourcedirectory, offers an extensive list of resources for patients and families about financial assistance, counseling, transportation, summer camps and other needs.

Co-Pay Assistance Program. This program offers assistance for financially eligible patients with certain blood cancer diagnoses to help pay for private or public health insurance premiums and/or co-pay costs for prescription medications. Check www.LLS.org/copay or call (877) 557-2672 to speak to a *Co-Pay Assistance Program* specialist for more eligibility information.

Chapter Programs and Services. LLS chapter offices around the United States and Canada offer support and education. Your chapter can arrange for peer-to-peer support through the *Patti Robinson Kaufmann First Connection Program*. The *Patient Financial Aid* program offers a limited amount of financial aid for qualified patients. Find your chapter by calling (800) 955-4572 or by visiting www.LLS.org/chapterfind.

Telephone/Web Education Programs. LLS provides a number of free, live telephone and web education programs presented by experts for families, parents of children with cancer and healthcare professionals. Visit www.LLS.org/programs for more information.

School Reentry. The *Trish Greene Back to School Program for Children With Cancer* is a program designed to increase communication among healthcare professionals,

school personnel, parents and patients to assure children with cancer a smooth transition back to school. For more information, visit www.LLS.org/backtoschool.

Reach Out. Parents and family members can reach out for support in several ways:

- LLS offers online Blood Cancer Discussion Boards, including a specific forum for parents whose child has cancer at www.LLS.org/discussionboard, as well as online chats at www.LLS.org/getinfo.
- Local or Internet support groups and blogs can provide forums for support.
- Parents of children with cancer and the children themselves often become acquainted with one another, and these friendships provide support.

Depression. Treatment for depression has proven benefits for people living with cancer. Depression is an illness that should be treated even when a person is undergoing cancer treatment. Seek medical advice if your mood does not improve over time—for example, if you or your child feel(s) depressed every day for a two-week period. Contact LLS or ask your healthcare team for guidance and referrals to other sources of help, such as counseling services or community programs. For more information you can contact the National Institute of Mental Health (NIMH) at www.nimh.nih.gov and enter “depression” in the search box at the top of the web page, or call the NIMH toll-free at (866) 615-6464.

We’d Like to Hear From You. We hope this booklet helps you. Please tell us what you think at www.LLS.org/publicationfeedback. Click on “LLS Disease & Treatment Publications—Survey for Patients, Family and Friends.”

Your Child – The Initial Diagnosis

The initial diagnosis may be one of the most challenging events for you, your child and your family. Your first concern may be, “What does this mean for my child?”

Children, regardless of their age, are usually aware when their health is causing concern for their parents and the medical staff. Your child may experience a variety of emotions in quick succession. Feelings such as anger, guilt, fear, anxiety and sadness are all common reactions.

Your child’s treatment will involve new people and experiences that may sometimes be frightening. Treatment of children with leukemia or lymphoma usually takes place in a hospital or clinic. Your child may be admitted to the hospital almost as soon as the diagnosis is known or suspected. For some children this is the first time they have been admitted to a hospital or stayed away from home for an extended period of time.

How much should I tell my child about cancer? It is important to talk with your child about his or her illness at an age-appropriate level. Some parents want to shield their child from information about the illness and treatment. Providing information to your child about the illness and treatment will help him or her build trust in both you and the treatment team, and to feel comfortable talking about fears and concerns.

Some parents feel that they should discuss the illness with their child but not use the word “cancer.” Keep in mind that your child will be taking part in his or her treatment and will fill in gaps of information with his or her imagination. Giving factual information helps to correct any false ideas about cancer and cancer treatment. Knowing about cancer and understanding the importance of treatment may help your child to cooperate and to learn, with your help, to get through difficult situations. Your child’s treatment team can help you explain the diagnosis and treatment to your child.

Should my child be included in discussions with the treatment team?

You may want to consider:

- Your child’s age when making this decision. Will your child be able to understand what is discussed?
- Your comfort and the need to get questions answered. If there is information that you are not comfortable discussing in front of your child – for example, the long-term prognosis – then you can arrange to have some time alone with the treatment team to talk about these issues.
- Your child’s style of coping. Not all children are the same, and their preferences about the amount of information they want and how they want to receive it may vary. If your child would like to be included in meetings with the treatment team, try to make every effort to do so. Allowing your child to participate in the decisions about receiving information will increase his or her sense of control and increase the opportunity to have his or her needs met. If your child would rather not be included in team discussions, then it is important to honor this request as much as possible.

Some ideas to help your child to cope with the initial diagnosis

- Provide your child with information at a level that matches his or her ability to understand. You may need to give your child information more than once. As children grow older, they may need and want to know more about their illness and treatment.
- Explain that all cancers are not the same. Many children, especially older ones, have heard of cancer. They may know of someone who has died from cancer. Children should be aware that cancers affecting older adults are different from childhood leukemia or lymphoma.
- Reach out to members of the treatment team, including social workers and child life specialists, for assistance if you are unable to answer any of your child's questions.
- If your child shows strong feelings about the diagnosis, such as anger or sadness, let them know that it is normal to have these feelings and that it is okay to express them.
- Let your child know that you will stay with him or her as much as possible. If you do need to be separated from your child for a time, explain this in advance and provide him or her with other forms of support in your absence, such as phone calls and photos.
- Help your child to recognize that the doctors and nurses are working to help him or her get well, even though they may have to do things that cause discomfort. Explain the reasons for tests and treatments.
- Introduce your child to treatment team members who provide psychosocial support. This may include a psychologist, nurse, social worker and/or a child life specialist. These team members may be able to help you find the right words to explain the diagnosis to your child. They may also help your child to better understand information about his or her illness through medical play or other activities.
- Arrange for phone calls, emails, letters, photos and visits from friends when your child is feeling up to it.
- If possible, ask the child's teacher to make a personal phone call, send a note or visit the child.
- Understand that at times your child may act as if there were nothing wrong. You may wonder if he or she understands what is happening. It is common for children to process information in small amounts. For some children, this is a way of coping that lets them go at their own pace.

Your Child – Coping with Change

Your child will need to cope with many changes after the initial diagnosis. One of the biggest changes your child will experience is a sense of loss of control over his or her world. It can be challenging for children of any age to be in an unfamiliar environment, to have to take medications or to undergo procedures that may be uncomfortable. Your child may also have to cope with fear and other feelings related to changes in appearance, such as hair loss or weight gain. The extent of your child's distress over any of these factors depends on your child's age and personality. Maintaining a supportive yet matter-of-fact attitude may help your child to adjust to and accept these changes.

School-age children are often unable to attend school for some period of time following a diagnosis of leukemia or lymphoma. School is a major part of a child's life, and the loss of social outlets, connection to friends, and play activities is upsetting for many children and may cause anxiety. Changes to the regular daily schedule can cause your child to feel upset and sad. When he or she is feeling up to it, your child can continue his or her education even if he or she is not able to attend classes. There are ways that you can support your child through these changes.

- Keep lines of communication open between your child's school, the hospital and home. For example, classmates and friends can maintain ongoing contact during the student's absence by telephone, email and texting, video chat, or they can create video messages for the child who is ill.
- It may be helpful to have a liaison who will be able to help school personnel understand the student's medical needs and can help the medical team understand any school-related issues. This person could be a social worker, psychologist, nurse, or school counselor.

Children with a serious illness are likely to exhibit behavior changes. Recognize that a child with leukemia or lymphoma continues to grow and develop during the course of his or her experience with the disease. Be aware of changes in your child's behavior, and address them as they occur. Talk with the treatment team if you recognize areas of difficulty for your child that you believe need to be addressed. Most hospital and treatment centers offer psychosocial support services for children with leukemia or lymphoma, or can refer you to such services in your community.

Don't hesitate to ask for additional assistance if your child is already working with a psychologist, social worker or child life specialist. Some children need extra support. It is not unusual for child life specialists, social workers and psychologists to work together to meet the needs of a child when that child is in distress or having continued difficulty with adjustment to the diagnosis and treatment.

What behaviors can I expect as my child copes with the changes that come with diagnosis and treatment?

- Children who tended to be moody and have tantrums prior to their illness are likely to have an increase in these behaviors.
- Some children are more prone to worry and may need extra reassurance.
- Children who tend to be withdrawn may become more withdrawn.
- Some children may regress to an earlier stage of development. For example, your child may want to sleep with a stuffed animal that he or she has not paid attention to for some time.
- Some children may want to have closer contact with a parent in a way they have not shown for some time.
- Some older children may seek privacy and have difficulty with parental concerns and monitoring related to their illness.
- Children may have difficulty sleeping as a result of anxiety and fear about medical interventions or their illness.

Some ideas to help your child to cope with change

- Help your child stay in touch with family and friends from school. Arrange for friends to have accurate information about your child's diagnosis and treatment. Create a blog or use free websites to help stay connected and provide appropriate and accurate information. Friends will feel more connected to your child when they are kept "in the loop." This will also help to keep misinformation from being circulated.
- If possible, have a member of the treatment team, such as a nurse, social worker, psychologist or child life specialist, go to the child's classroom to explain the child's diagnosis and treatment and how these will affect the child's attendance in school. If such a class presentation is possible, ask the child first if he or she would like this to be done.
- Provide structure to increase your child's sense of control. Children crave structure in their environment. Whenever you can, keep things as consistent as possible. For example, you might have a routine – based on your child's age and interests – for how you spend your time together in the hospital or clinic. Recognize that giving your child gifts all the time, or stopping all previous forms of discipline, is confusing to the child.
- Give your child the chance to make choices whenever possible. For example, your child does not have a choice about whether or not to take medicine but might have a choice about which pill to take first. It may even be possible that your child can choose the timing of some forms of treatment. Your

child can also make certain food choices, select movies to watch and books to read.

- Take advantage of opportunities to acknowledge and praise your child when he or she is doing things that are difficult. The best way to reinforce behaviors that you want your child to continue is to give praise intermittently for things that are difficult.
- Give your child appropriate outlets to express feelings. He or she may want to draw, make up stories, keep a journal/diary or have a doll that is used just for medical play to express feelings and fears.
- At times your child's feelings may contribute to "acting out" behaviors. You can set limits (whether your child is sick or well) while showing that you respect his or her feelings of anger, worry, sadness or fear. Let your child know that you expect him or her to act appropriately toward other people. This will help your child both now and later, when he or she begins to feel better. Parents who ignore all rules related to behavior when their child is sick have a more difficult time with behaviors when their child gets better. Children will also have a more difficult time if they are able to do whatever they want for months and are then expected to go back to school, follow rules and relate to peers.
- Use distracting activities to assist your child with treatment. Children often feel anxious about medications, chemotherapy, needle pokes and other interventions. Keep their focus away from the distressing experience and on enjoyable activities to reduce their anxiety. On the days that your child has outpatient treatment, such as chemotherapy at the clinic, bring materials to keep your child busy.
- Ask for assistance to help your child if he or she is having an especially difficult time adjusting to the diagnosis and treatment.

Parents — Coming to Terms with Your Feelings

Your child's cancer diagnosis may produce a jumble of reactions for you – including shock and confusion, denial, fear, anxiety, anger, grief and sadness. Your sense of security and your religious or spiritual beliefs may be shaken. Many parents experience this mix of feelings throughout their child's illness. All are valid reactions to this situation.

You and other members of your family may experience feelings of guilt and wonder whether you have done something to cause your child's illness. It is important to remind yourself and your family members that no one is to blame.

Throughout this experience, you will need to explain the disease and treatment to your child and find ways to comfort him or her. You will need to help your child cooperate with medical treatment. Your other children may need you to explain what is happening to their brother or sister. You may have to answer relatives' questions and perhaps make alternate arrangements for work and child care. All along the way, you will be coming to terms with your own feelings and choices. None of this is easy.

It is common for family members, including parents, to react differently from one another after the initial diagnosis. Each person is an individual with his or her own way of expressing emotion, and there is no right way to feel or react. Parents often balance each other: one may be the worrier while the other remains calm. Given the intensity of the experience, the emotion it evokes and the number of important decisions to be made, it is likely parents, and other family members, will disagree at times.

Disagreements need to be resolved so that you can give your child support. Resolving differences should not be thought of as a win-or-lose situation but as a means to provide the best care for your child. If parents are having problems with their relationship, they need to find a way to set aside conflicts and cooperate in caring for their child. Access to a good network that provides support and time for personal rest and relaxation is essential whether you are a single parent, part of a couple, or a separated or divorced parent. Many families find social support from relatives, friends and/or religious or spiritual groups.

Parents often find other parents who have sick children to be a source of support. Parents of children with cancer are a unique group. Few people can understand what parents are going through as well as other parents who have a child with a similar diagnosis.

In many hospitals, parents get to know each other while their children are hospitalized or in the clinic. Some parents join or organize parent support groups that meet on a regular basis. There are also many online chat groups for parents of children with a specific diagnosis and treatment. These contacts may help parents cope with many aspects of their child's diagnosis and treatment, as well as with family and work issues.

If you do not have a support network, talk to members of your child's treatment team about finding support resources. In many communities, there are special support programs. You can also contact our Information Specialists, your chapter or find information online at www.LLS.org.

Some coping strategies for parents. Here are suggestions for managing some of the feelings, emotions and reactions that parents may experience.

Shock and confusion. The information you are given about your child's illness is often very complicated. When a parent hears the word "leukemia" or "lymphoma" and learns that his or her child has cancer, it often causes the parent to initially block out other information about the child's illness. Healthcare professionals understand this reaction. Ask them to repeat information, whenever necessary, as your questions arise.

- Some parents take notes or audio-record their meetings with their child's treatment team so that they can review what they have been told and share it with other family members.
- Many families find it helpful to keep a notebook with the important information all in one place and to include the business cards of medical and other professionals. It may also be helpful to create a calendar of your child's treatment schedule and medications. Keeping track of information in these ways allows you to review it as many times as you need to.

Denial. Most parents would like to believe that their child's cancer diagnosis was a mistake. For a short time, denial about the accuracy of the diagnosis may help parents to adjust and shift gears. However, parents staying in denial for too long may isolate both the child and other family members at a point when communication is very important.

Before the child begins treatment, some parents seek a second opinion or request additional information about the credentials of treating physicians or the medical center, along with the number of patients treated and their outcomes. In many cases, this approach may be helpful; however, it is important to schedule consultations or obtain additional information in a timely manner. Healthcare professionals are generally willing to help arrange this.

Hope. Hope plays an important role in the ability to cope, particularly in trying times. A physician wrote, "Hope of improvement is the motivation behind accepting every dose of medication prescribed." Hope provides strength and helps us to maintain the will to live.

Talking with other parents whose children have had a similar diagnosis or gone through similar treatment and are now cured can sometimes be helpful. The knowledge that other children with similar illnesses are cured, and that your child also has a good chance to be cured, can inspire hope.

Fear and anxiety. You may experience many fears and worries, including concerns about your child's treatment outcome, the health of your other children,

finances, major changes in daily responsibilities or employment, how relatives and friends will react, how your child will cope with treatment, and your ability to handle the situation. If you have been referred to a large medical center for complete diagnosis and treatment, you may have to cope with a new hospital and medical team, perhaps in an unfamiliar city or town.

- Some people find it helpful to talk about their fears and anxieties. Others prefer reading books or other information about the disease and treatment. Your child's treatment team includes professionals trained to help you discuss, or gather information, about all aspects of your child's illness: physical, emotional and financial. Enlist their support – they want to help you.
- Relatives and friends can often be a source of strength and understanding. However, some mean well but are not very helpful. They may deny the illness, offer homemade remedies or disapprove of your choices. Enlist the assistance of professionals to cope with friends or relatives who are not supportive.

Anger. Don't be surprised if you feel angry at times. Parents of children who are seriously ill say they have experienced anger about why this happened to them, anger at their child's physician or the entire medical profession for the difficult treatments, frustration with their health insurance company or with the healthcare system, anger that their innocent child has to suffer, or even anger at their child for becoming ill or at God for not protecting their child from the illness.

- Often there is no direct outlet for these angry feelings. As a result, emotions may be misdirected toward family members, co-workers or even complete strangers.
- Talking about angry feelings with trusted friends, relatives and professionals is one way you can learn to accept these feelings. This will help you to take constructive action when possible. Seek support from other parents in similar situations. When there are issues that spark your anger, try to work with your child's treatment team to change situations or resolve problems.
- Physical activity or exercise, journal writing and finding private space to vent feelings are all good ways to cope and manage the stress you are experiencing. Join a parent support group to gain tips and suggestions from parents whose children are going through similar treatment.

Guilt and blame. Some parents may react to the stress of their child's cancer diagnosis by looking for a cause or for someone or something to blame for the cancer. Almost all parents experience guilt – although perhaps for different reasons. You may think you might have passed on bad genes or done something wrong that caused the cancer to occur. You may dwell on past regrets. You may blame yourself for not paying more attention to your child's symptoms and seeking a medical evaluation sooner. However unbelievable, some family members and friends may even tell you that something you or your spouse did caused your child's cancer.

- Acknowledge any feelings of guilt you may have so that you can get the information, comfort and support you need. As hard as it is to accept, you may

never know what caused your child's cancer. Remind yourself and your family that no one is to blame.

- If you or a family member is experiencing these feelings, it is important to get support from healthcare professionals in order to gain a better understanding of your child's illness. Psychologists, social workers and spiritual advisors may also be able to help you come to terms with your child's diagnosis.
- If friends or family members blame a family member for the cancer diagnosis, it is important to remember that they are not correct and that they are trying to make some sense out of the situation, however wrong or inappropriate their reasoning.

Sadness and loss. From the moment the diagnosis is made, you may feel a sense of loss. You may come to a realization that life for your child and family will never be quite the same. It is normal to have these feelings. Over time, you will find ways to adapt and gradually develop a new sense of normalcy for you and your family.

- Allow yourself to feel sad when a sense of loss overwhelms you. However, if you feel consumed by this emotion or are unable to function well, seek professional help. It is important to work through your feelings so that you can help your child cope and you can manage other aspects of family life and work.

Doubts about religious and spiritual beliefs. Your child's illness may seem unfair. The seeming injustice can lead you to question your views on the meaning, purpose and value of life, or your spiritual beliefs and relationship with God. You may feel empty, cynical or discouraged.

- Exploring these feelings with the aid of a counselor or spiritual advisor is helpful for many parents.

Siblings – Helping Them Cope Too

Brothers and sisters (siblings) of the child with leukemia or lymphoma can feel lost or overlooked. It may seem that life for the sibling should go on as normal – with school, after-school activities and chores. However, siblings are also affected by the cancer experience, and they may develop problems as a result.

One or both parents may be spending a lot of time at the hospital with the sick child. Siblings may be concerned about getting help with homework, transportation to and from school and activities, and how meals and food shopping will get done. They may feel guilty about being healthy, about resenting the attention their sibling with cancer is getting and/or about their own needs for their parents' help and attention. Siblings may also feel angry, anxious, lonely or sad at various times during the cancer experience. They may have difficulties with self-esteem, with school or with friendships.

While sibling reactions of some kind are inevitable, you can help by making sure that siblings receive your attention as well as information and social support, and that they have the opportunity to talk about how cancer is affecting them and other members of the family.

Siblings need to continue to go to school and participate in their usual after-school and weekend activities as much as possible. This may require the assistance of family and friends. It is important that you communicate with your children's teachers, coaches and other adults who interact with your children so that they are aware of the situation and can provide support.

Some ideas to help brothers and sisters to cope

- Be honest about the cancer diagnosis and treatment. Kids are very savvy and will come to their own conclusions if they think they are not being told the truth.
- If possible, introduce siblings to the treatment team, who can help give medical information and reinforce that the siblings are special.
- Give information that is age appropriate. Don't be overly concerned about giving too much information. Children, like adults, stop listening when they've heard enough. Children may worry about cancer being contagious and may need reassurance that they cannot catch it. Explain that there is nothing anyone did to cause the cancer.
- Let siblings know when a hospitalization or long clinic day is anticipated.
- Be open and willing to answer questions as treatment continues.
- Let siblings know where they will be staying (if not at home) and who will be staying with them. Explain any other arrangements that have been made to provide for their care in view of the changed family routine.
- Whenever possible, give siblings the opportunity to express where they would like to go after school and whom they would like to care for them when parents are not available.
- Ask family, friends or neighbors to help get siblings to their usual activities, such as soccer practice or piano lessons.
- Arrange for "alone time" with the well sibling. Even if brief, this is something that the well sibling can count on and look forward to.
- When possible, involve siblings in the treatment and arrange for them to visit the hospital or clinic. They can feel helpful by spending time with their brother or sister, and may enjoy playing board games or watching TV or a movie together.

- Make sure school teachers, nurses and guidance counselors in each of your children's schools know what is happening. Do not assume that they communicate with one another.
- Help your children identify a "safe" person at school to talk to when they are feeling scared or sad. Request a hall pass so that the children are able to leave class to talk to that person when needed.
- Ask your hospital's social worker or psychologist, or your school psychologist, if your community has programs especially for siblings of children with cancer. LLS has a listing of helpful resources that includes organizations to help siblings cope. To access Other Helpful Organizations, go to www.LLS.org/resourcedirectory.
- Remember that brothers and sisters still have their own problems, unrelated to their sibling's cancer, that are real and require your attention.
- Provide consistent, fair discipline. This is just as important as ever, even though it may be more difficult right now.
- Let siblings know that you love them and are proud of them.

Communicating with Your Extended Family and Friends

Sharing the news that your child has cancer can be overwhelming. These are words you never imagined having to say. However, having the support of family and friends will help you and your child get through treatment. Most people want to help, even though they often need direction about how to help.

Some ideas for communicating with friends and family

- Identify a family member or friend, who can become your "press secretary." This person will be the individual who will get the latest information out to others so that you can focus on your family.
- Technology can be your friend.
 - Many organizations, including LLS, provide Internet-based discussion boards, (www.LLS.org/discussionboard) through which you can share information and receive support without being overwhelmed by questions and phone calls.

- LLS also offers Other Helpful Organizations at www.LLS.org/resourcedirectory, which is a directory that includes organizations that can help you connect with family and friends.
- Group emails to family and friends are also helpful and efficient.
- Let people help you. You may not be comfortable at first. But when someone offers to cook a meal, cut your grass or do the laundry, let them.
- Keep a list of chores that you can use help with – no matter how small. Then when someone says, “What can I do to help?” you will have an answer.
- Keep a list of people who offer to help. Call them when a need arises. Remember, they want to help.
- Talk with other parents whose children have similar diagnoses or treatment. Social workers in the treatment center can introduce you to these parents. The Leukemia & Lymphoma Society’s *Patti Robinson Kaufmann First Connection Program* (www.LLS.org/supportgroups) enables patients and their loved ones to connect with a trained peer volunteer who has gone through a similar experience. Keep in mind, however, that no two children or families are exactly alike.

The New Normal

The return to so-called normal life after treatment ends, when there is no longer need for daily or weekly visits to the hospital or clinic, can be another challenging time for you and your child. Although follow-up visits are important and will continue for life, when active treatment is over, a child is usually expected to pick up his or her old life where it left off. This means readjusting to the home routine, social activities and school. Although the transition may go quite well overall, there are likely to be stressful times as your child deals with the challenges of multiple tasks and responsibilities.

You may see changes in your child’s self-esteem during the return to normal life. A child who may have felt competent and secure prior to illness, or even during active treatment, may now feel insecure and more dependent. He or she may feel embarrassed because of changes in appearance and the responses of some friends or classmates. Your child may become more aware of the stresses he or she has experienced due to the illness and may begin to process changes and losses that have occurred. During this time, the child may also experience changes in attention from family, caregivers and school staff as he or she begins to resume the roles of child, sibling, student and friend. Gradually, he or she will no longer be thought of as “the child with cancer who needs additional attention.”

How can I help my child with the transition to “normal” life? You can help your child to cope with the challenges he or she is facing.

- Observe and recognize changes in your child’s behavior when and if they occur.
- Talk to your child about his or her feelings and let your child know that it will take time to adjust to all the changes that have taken place.
- Provide your child with support and encouragement, and obtain extra support from a therapist if problems persist. Feelings of anxiety, depression and recurrent thoughts or fears regarding the illness and its treatment should be explored.
 - Is your child anxious regarding the return to school and the reaction of peers?
 - Is he or she having difficulty sleeping or frequent nightmares?
 - Is your child quick to have tantrums and frequently tearful?
 - Is he or she spending more time alone?

If your child seems to be experiencing difficulty in these areas, he or she may need some additional support.

Support at home will help your child navigate through the challenges on the road back to normal life. Provide structure for your child by establishing a routine to help him or her return to previous activities and cope with new experiences.

How can I provide structure and support for my child at home?

- A nightly bedtime routine helps your child to get the proper amount of sleep and will help make him or her feel safe.
- Establish an after-school routine, such as homework at the same time every day, a time for relaxing with a favorite show or activity, or dinner at a regular daily time.
- For a younger child, it may be helpful to give cues about what will come next; for example, “In five minutes it will be time to start homework.” Or, “When we get home we will do homework and then have play time, then dinner, and then bath and bed.”
- Help your child to identify goals as he or she resumes daily home and school activities.
- Reinforce your child’s efforts to work toward achieving his or her goals.
- Allow your child to discuss difficulties and challenges.
- Help your child to recognize the progress that he or she is making.
- Let your child know that you love and are proud of him or her.

Going back to school. For most children, returning to school brings up fears about the reaction of friends and other children, missed schoolwork and social activities, changes in abilities, changes in appearance and new routines.

Discuss any fears your child may have about school before he or she returns. Help him or her develop coping strategies for various situations he or she might face. For example, if your child has visible changes from cancer treatment, he or she should be told that teasing may occur. Helping your child to learn ways to cope with teasing, and whom to talk to about it, will provide a sense of control over the situation if it occurs.

You will need to be the mobilizing force behind your child's education plan. You will need to see that a plan is started, maintained or changed as needed. Your child's treatment team and school personnel will support you in shaping and carrying out the plan.

How can I help my child with the return to school?

- Reach out to the treatment team; many hospitals provide support to assist your child as he or she returns to school. When your child is ready to return to school, or even before, it may be helpful to have a class presentation that is age-appropriate. This will help school friends and classmates learn that it is okay to discuss the illness. The presentation can be prepared, and possibly given, with the aid of a medical team member, who can assist with using language and concepts that the class can understand. If your child has physical differences as a result of treatment, such as hair loss, weight gain or scars, it may be helpful to include this topic in the talk with students. Your child can participate in a way that makes him or her comfortable.
- Before your child returns to school, meet with school administrators, teachers and counselors to make sure the staff is aware of your child's medical condition and that any special needs or concerns are addressed.
- Allow your child to meet with his or her teacher(s) prior to returning to school in order to reduce anxiety.
- Ask school staff to promptly identify any issues that may arise and provide you with any necessary information.
- Ask your child's physician to write a letter outlining any physical limitations or medical needs your child has, such as the need for extra snacks, water or bathroom breaks.

The LLS program *The Trish Greene Back to School Program for Children With Cancer* was developed to assist school or hospital staff with class presentations. *Staying Connected: Facilitating the Learning Experience During and After Cancer Treatment* is an education program about emotional, physical and cognitive late effects of treatment. The LLS free publication, *Learning & Living With Cancer: Advocating for your child's educational needs* provides information to help parents with education challenges and addresses ways that schools can help. For more information about these resources, visit www.LLS.org or contact our Information Specialists at (800) 955-4572.

Follow-up visits. The end of active treatment is stressful for many parents and children. There is every hope that your child will remain cancer-free. Your child's follow-up visits are now part of the new normal. These appointments may cause anxiety for you and your child. Worries just before visits about what could happen if the cancer came back are common. Anxieties will be reduced as more time passes since your child's cancer treatment and more "good" check-ups take place. You may also want to read and discuss The Children's Oncology Group's *Long-Term Follow-Up Guidelines for Survivors of Childhood, Adolescent, and Young Adult Cancers* (available at www.survivorshipguidelines.org) with your child's treatment team. The guidelines provide recommendations for screening and management of potential late effects of treatment.

Soon after treatment ends, you may begin to recognize that there is no one set point at which your child's cancer experience ends. This is a gradual process that takes place over time, perhaps years. You can talk with your treatment team about any fears to gain assurance when possible. Recognize that your fears and anxieties are a normal part of the process. Help your child to talk about his or her fears, anxieties, anger and hopes with you and the treatment team.

Without a doubt, the new normal is a time of adjustment for parents and children. You begin to understand some of the ways life will be forever changed due to the cancer experience. With your help, children are able to see that they can move forward and grow with an enhanced understanding of themselves and life.

More Information

Free LLS publications include

The ALL Guide: Information for Patients and Caregivers

The AML Guide: Information for Patients and Caregivers

Blood and Marrow Stem Cell Transplantation

The CML Guide: Information for Patients and Caregivers

Financial Health Matters

Knowing All Your Treatment Options

Learning & Living With Cancer: Advocating for your child's educational needs

Long-Term and Late Effects of Treatment for Childhood Leukemia or Lymphoma

Pictures of My Journey - Activities for Kids With Cancer

The Lymphoma Guide: Information for Patients and Caregivers

The Stem Cell Transplant Coloring Book

Understanding Clinical Trials for Blood Cancers

Understanding Drug Therapy and Managing Side Effects

Resources

In addition to our programs and services for blood cancer patients, families and caregivers, The Leukemia & Lymphoma Society (LLS) is pleased to offer an extensive directory of national resources that can help with cancer-related issues like financial assistance, support and counseling, assistance with transportation and summer camps, as well as finding survivorship guidelines or understanding disability laws. Please see our directory of Other Helpful Organizations at www.LLS.org/resourcedirectory.

Books and Pamphlets

To obtain a copy of these materials, go to the website provided. If a publisher is listed, obtain a copy through your local bookstore or library. Visit "Suggested Reading" at www.LLS.org/resourcecenter to see helpful books on a wide range of topics.

For Children and Teens

The Jester Has Lost His Jingle

by David Saltzman

A story about finding laughter and happiness inside oneself to help get through challenging times such as a cancer diagnosis. Useful tool for classroom presentations.

Published by Jester Books.

www.thejester.org

What IS Cancer Anyway? Explaining Cancer to Children of All Ages

by Karen L. Carney

Provides basic, reassuring information about cancer in simple terms.

Published by Dragonfly Publishing, Inc.

For Parents and Teachers

A Parents and Teacher's Guide for Kids With Cancer

Explains social and academic challenges childhood cancer survivors face and outlines strategies for successful school reintegration.

Available at www.cancervive.org.

Childhood Cancer Survivors: A Practical Guide to Your Future

by Nancy Keene, Wendy Hobbie and Kathy Ruccione

Published by O'Reilly & Associates, Inc.

Childhood Leukemia: A Guide for Families, Friends, & Caregivers (4th edition)

by Nancy Keene

Published by O'Reilly & Associates, Inc.

Educating the Child With Cancer: A Guide for Parents and Teachers

by Nancy Keene

Available at www.acco.org.

Living With Childhood Cancer: A Practical Guide to Help Families Cope

by Leigh A. Woznik and Carol D. Goodheart

Published by the American Psychological Association.

100 Questions & Answers About Your Child's Cancer

by William L. Carroll

Published by Jones & Bartlett Publishers.

Young People With Cancer—A Handbook for Parents

Available at www.cancer.gov.

Videos and DVDs

Back to School

Available at www.starlight.org.

Emily's Story: Back to School After Cancer

and

Making the Grade: Back to School After Cancer for Teens

Available at www.cancervive.org.

Why Charlie Brown, Why: A Story About What Happens When a Friend Is Very Ill

Available from The Leukemia & Lymphoma Society.



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REACH OUT TO OUR **INFORMATION SPECIALISTS**

The Leukemia & Lymphoma Society's (LLS) Information Specialists provide patients, families and healthcare professionals with the latest information on leukemia, lymphoma and myeloma.

Our team consists of master's level oncology professionals who are available by phone Monday through Friday, 9 am to 6 pm (ET).

Co-Pay Assistance

LLS's Co-Pay Assistance Program helps blood cancer patients cover the costs of private and public health insurance premiums, including Medicare and Medicaid, and co-pay obligations. Support for this program is based on the availability of funds by disease.

**For more information,
call 877.557.2672 or
visit www.LLS.org/copay.**

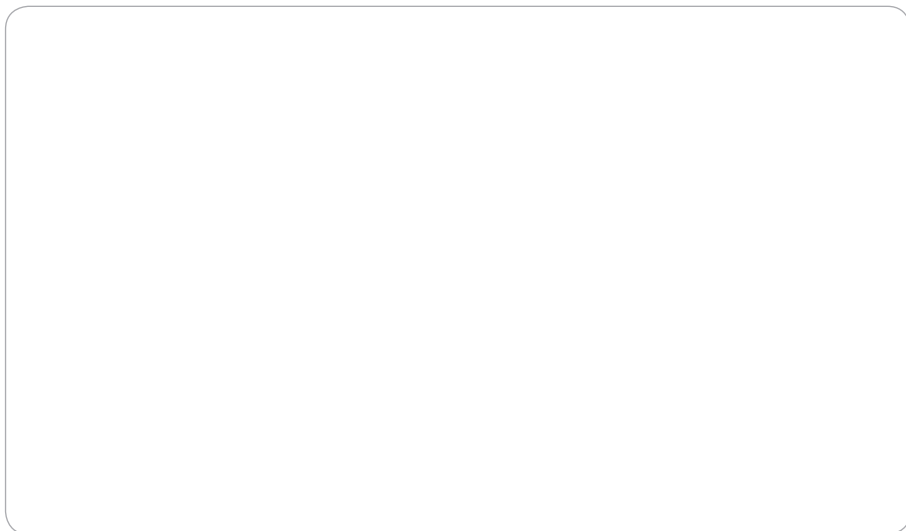


For a complete directory of our patient services programs, contact us at

800.955.4572 or www.LLS.org

(Callers may request a language interpreter.)

For more information, please contact:



or:

National Office

1311 Mamaroneck Avenue, Suite 310, White Plains, NY 10605

Contact our Information Specialists **800.955.4572** (*Language interpreters available upon request*)

www.LLS.org

Our Mission:

Cure leukemia, lymphoma, Hodgkin's disease and myeloma, and improve the quality of life of patients and their families.

LLS is a nonprofit organization that relies on the generosity of individual, foundation and corporate contributions to advance its mission.