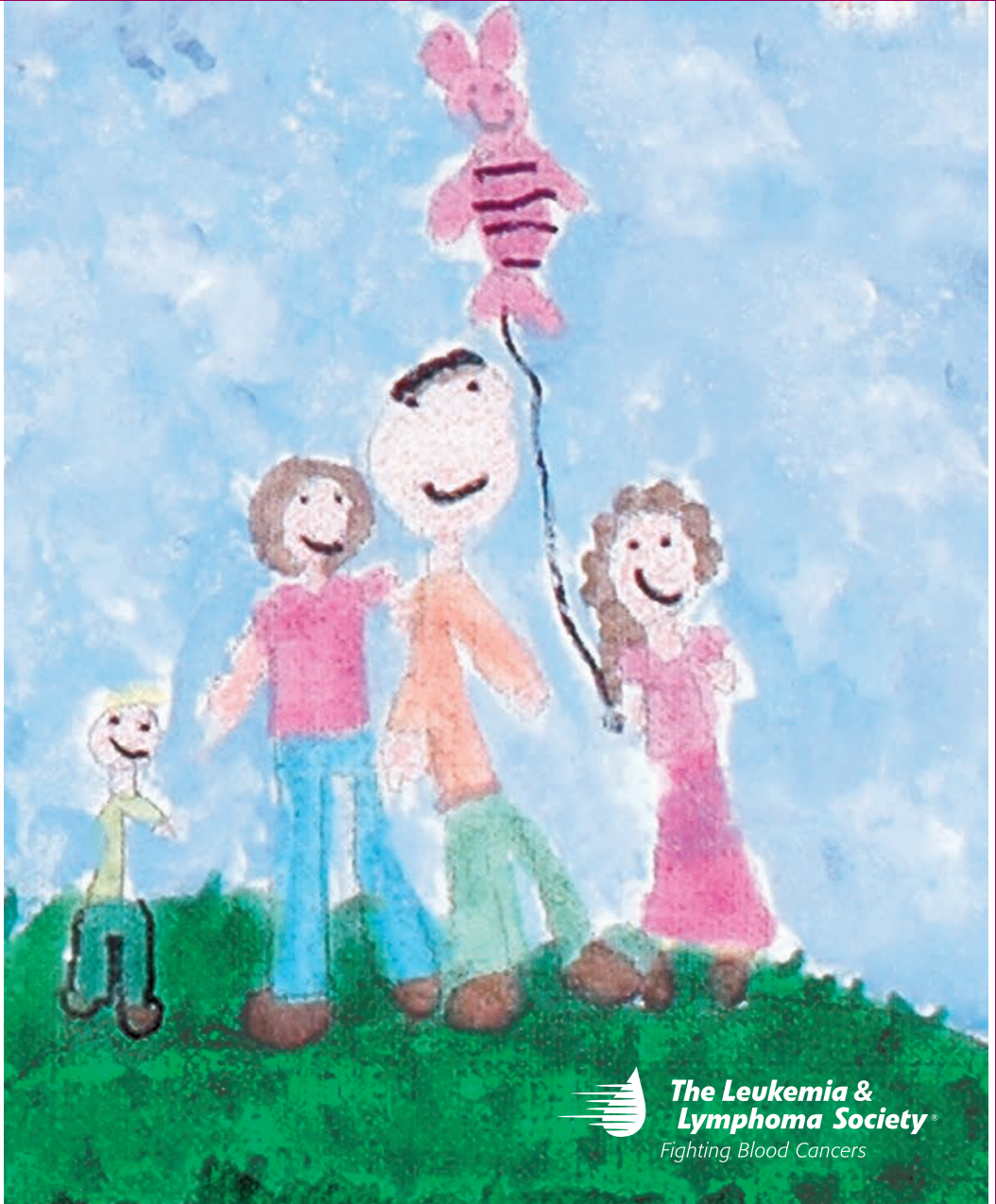


# Coping With Childhood Leukemia and Lymphoma

LEUKEMIA

LYMPHOMA

MYELOMA



**The Leukemia &  
Lymphoma Society**  
*Fighting Blood Cancers*

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# Introduction

Families face uncertainty when they are told that their child has leukemia or lymphoma. 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 due to new and better treatments. Doctors, nurses and scientists are working together around the world to continue to improve outcomes for children diagnosed with leukemia or lymphoma – researchers continue to search for the causes, develop better treatments and tailor therapies to 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.

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.

# 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 medical centers’ inpatient units and outpatient clinics. Your child may be admitted to the hospital almost as soon as the diagnosis is known. For some children this is the first time they have 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 to 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 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.

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

Some factors you may want to consider are:

- Consider your child’s age when making this decision. Will your child be able to understand what is discussed?
- Consider your comfort and 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 team to talk about these issues.
- Consider your child’s style of coping. Not all children are the same, and their preferences about the amount of information and how they receive it 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 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.
- Encourage your child to talk about fears and concerns, and answer his or her questions.
- Acknowledge your child's behaviors and emotions as they arise.
- 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 pain. 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 or painful. 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.

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. Changes to the regular daily schedule can cause your child to feel upset and sad. There are ways that you can support your child through these changes.

Children with a serious illness are likely to experience 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 have an increase in this behavior.
- Some children may regress to an earlier stage of development. For example, your child may want to sleep with a stuffed animal that has not been noticed 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 have difficulty with parental concerns and monitoring.
- Children may have difficulty sleeping as a result of anxiety and fear about medical interventions or their illness.

## Some ideas to help your child cope with change

- Help your child to stay connected with friends from home and school. Arrange for friends to have accurate information about your child's diagnosis and treatment. 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. When you can, make things as consistent as possible for your child. 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. Your child can also make certain food choices and select movies to watch and books to read. At times you may be able to give your child a choice about the timing of some forms of treatment.
- Take the opportunity 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 for your child (whether he or she 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 the children are sick have a more difficult time with behaviors when their children get 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. During outpatient treatment, bring materials to keep your child busy on the days that he or she has chemotherapy at the clinic.
- 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 your situation.

You and other members of your family may have feelings of guilt, wondering if you may 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. You may need to explain what is happening to your other children, 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 to 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, with one being the worrier and the other one remaining calm. Given the intensity of the experience, the emotion it evokes and the number of important decisions to be made, it is likely you 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. When 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 with sick children a source of support. Parents of children with cancer are a unique group. Few people can understand what you are going through as well as other parents who have a child with a similar diagnosis. This understanding cuts across social, economic and racial barriers.

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 your child's treatment team about finding support resources. In many communities, there are special support programs. You can also contact The Leukemia & Lymphoma Society's Information Resource Center (IRC) or your local Society Chapter or find information online at [www.LLS.org](http://www.LLS.org).

## **Some coping ideas 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. Ask them to repeat information, whenever necessary, as your questions arise.

Some parents take notes or tape-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 all of this important information and to include the business cards of medical and other professionals. This allows you to keep track of everything so that you can go back and review information as many times as needed.

- **Denial**

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

Before beginning treatment, some parents seek a second opinion or request additional information about the credentials of treating physicians or the medical center. In many cases, this 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 have now recovered can sometimes be helpful. The knowledge that other children with similar illnesses have recovered, and that your child also has a good chance for recovery, 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 institution 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 talk, 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 deal 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.

- **Guilt and blame**

Some parents may react to the stress of the 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 to get 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 so that 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

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, 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, meals and shopping. 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 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 too.
- Give information that is age appropriate. Don't be overly concerned about giving too much information. Children, like grown-ups, 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 that the child can count on.
- Involve siblings in the treatment if possible and arrange for them to visit the hospital when possible. They can feel helpful by spending time with their brother or sister 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 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.
- 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 The Leukemia & Lymphoma Society, provide Internet-based discussion boards through which you can share information and receive support without being overwhelmed by questions and phone calls. Group e-mails 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 has a *First Connection Program* that can also help with this. 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. He or she begins to resume the roles of child, sibling, student and friend. Gradually, he or she is no longer 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, 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 to 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 at school, 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 begins. 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 can help 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 need for extra snacks, water or bathroom breaks.

The Leukemia & Lymphoma Society's *Trish Greene Back to School Program for Children With Cancer* was developed to assist school or hospital staff with class presentations. *Welcome Back: Facilitating the School Experience for Childhood Cancer Survivors* is an education program about emotional, physical and cognitive late effects of treatment. The Society's free booklet, *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, contact your local chapter. Visit the Society's Web site at [www.LLS.org](http://www.LLS.org) or contact the Society's Information Resource Center at (800) 955-4572 to locate a chapter in your area.

## 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 would 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](http://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.

# We're Here to Help

The Leukemia & Lymphoma Society also offers services through its local chapters and national office to help ease the emotional and economic pressures that come with a diagnosis of leukemia, lymphoma or other blood cancers. The Society provides financial assistance, education programs, printed materials and videos for children, parents and educators. Services include the Information Resource Center (IRC), staffed with social workers and health educators who offer callers up-to-date, accurate disease-related information. The Society's network of chapters is located throughout the United States and Canada. Visit the Web site at [www.LLS.org](http://www.LLS.org) or contact the IRC at (800) 955-4572 to locate a chapter in your area, order free publications or speak directly to an Information Specialist.

## **The Leukemia & Lymphoma Society free publications include:**

*Acute Lymphocytic Leukemia: A Guide for Patients and Families*

*Acute Myelogenous Leukemia: A Guide for Patients and Families*

*Blood and Marrow Stem Cell Transplantation*

*CML: A Guide for Patients and Caregivers*

*Financial Health Matters*

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

*Long-Term and Late Effects of Treatment for Blood Cancers fact sheet*

*Pictures of My Journey - Activities for Kids With Cancer*

*The Lymphomas: A Guide for Patients and Caregivers*

*The Stem Cell Transplant Coloring Book*

*Understanding Clinical Trials for Blood Cancers*

*Understanding Drug Therapy and Managing Side Effects*

# Resources

## **Camp Sunshine**

207-655-3800 [www.campsunshine.org](http://www.campsunshine.org)

Provides respite, support, joy and hope to children with life-threatening illnesses and their immediate families through various stages of a child's illness. The free, year-round program includes 24-hour on-site medical and psychosocial support.

## **CancerCare**

800-813-4673 [www.cancer.org](http://www.cancer.org)

A national nonprofit organization that provides free, professional support services for anyone affected by cancer.

## **Cancervive<sup>®</sup>, Inc.**

310-203-9232 [www.cancervive.org](http://www.cancervive.org)

Dedicated to helping cancer survivors reenter school or the workplace. Cancervive offers books and videos for adults, teens and children; an "Ask the Expert" e-mail for legal questions; and a listing of scholarships for cancer survivors.

## **Candlelighters<sup>®</sup> Childhood Cancer Foundation**

800-366-2223 [www.candlelighters.org](http://www.candlelighters.org)

Offers support, education and advocacy for children and adolescents with cancer, survivors of childhood cancer, their families and the professionals who care for them.

## **CureSearch**

800-458-6223 [www.curesearch.org](http://www.curesearch.org)

Represents the Children's Oncology Group (COG) and the National Childhood Cancer Foundation (NCCF). Supports lifesaving research and helps raise awareness of the importance of cancer clinical trials. Provides online information on types of childhood cancer and treatments.

## **Lance Armstrong Foundation (LAF)**

512-236-8820 [www.livestrong.org](http://www.livestrong.org)

Provides practical information and tools; serves its mission through advocacy, public health and research.

## **Learning Disabilities Association of America**

412-341-1515 [www.ldanatl.org](http://www.ldanatl.org)

Started by parents, the association offers parents information on learning disabilities, negotiating the special education process and helping your child and yourself. Includes an online training course about the Individuals With Disabilities Education Act (IDEA).

## **LIVESTRONG™ SurvivorCare**

866-235-7205 [www.livestrong.org/survivorcare](http://www.livestrong.org/survivorcare)

Helps cancer survivors and family members face the everyday challenges of survivorship through emotional support, individual counseling, and assistance with financial, legal and/or insurance issues and matching to clinical trials.

## **National Dissemination Center for Children with Disabilities**

800-695-0285 [www.nichcy.org](http://www.nichcy.org)

Provides information on childhood disabilities, the laws protecting children's rights and research-based educational practices.

## **Patient Advocate Foundation**

800-532-5274 [www.patientadvocate.org](http://www.patientadvocate.org)

Seeks to safeguard patients through effective mediation assuring access to care, maintenance of employment and preservation of their financial stability.

## **Starlight Starbright™ Children's Foundation**

800-315-2580 [www.starbright.org](http://www.starbright.org)

Creates innovative, media-based programs that help seriously ill children and teens better cope with their disease and enhance their quality of life. Offers free CD-ROMs and online communities of information and support for kids and parents.

## **Surviving and Moving Forward: The SAMFund for Young Adult Survivors of Cancer**

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

Helps support young adult cancer survivors in the transition from high school to college. Offers financial assistance through grants and scholarships.

## **The Ulman Cancer Fund for Young Adults**

888-393-FUND (888-393-3863) [www.ulmanfund.org](http://www.ulmanfund.org)

Addresses areas of cancer support, advocacy and education for young adults dealing with cancer. Connects young adults affected by cancer. Offers financial assistance through grants and college scholarships.

## **Additional Web Sites**

*The following Web sites may also be helpful.*

### **For Children and Teens:**

#### **[www.grouploop.org](http://www.grouploop.org)**

Sponsored by The Wellness Community®. Provides online support, information and resources for teens with cancer and their parents.

#### **[www.lehman.cuny.edu/faculty/jfleitas/bandaides/stories.html](http://www.lehman.cuny.edu/faculty/jfleitas/bandaides/stories.html)**

Features stories from children, teens and siblings about living with serious illness.

#### **[www.planetcancer.org](http://www.planetcancer.org)**

Planet Cancer offers online support and resources for young adults with cancer.

#### **[www.supersibs.org](http://www.supersibs.org)**

A foundation that honors, supports and recognizes brothers and sisters of children with cancer.

#### **[www.teenslivingwithcancer.org](http://www.teenslivingwithcancer.org)**

Sponsored by Melissa's Living Legacy Foundation. Offers teens a place to get cancer facts, connect with others and share stories of hope and inspiration.

### **General:**

#### **[www.acor.org/ped-onc](http://www.acor.org/ped-onc)**

For parents, friends, and families of children who have or have had childhood cancer.

#### **[www.bravekids.org](http://www.bravekids.org)**

Offers an online community and Web resource center for children with special needs, their families and healthcare professionals.

**[www.cancer.gov](http://www.cancer.gov)**

Provides information about childhood cancer and treatment.

**[www.outlook-life.org](http://www.outlook-life.org)**

Provides advocacy and information to help childhood cancer survivors and their families confront issues related to their experience after treatment has ended.

**[www.survivorshipguidelines.org](http://www.survivorshipguidelines.org)**

This site provides guidelines for healthcare providers for the screening and management of late effects related to cancer treatment.

**Legal:**

**[www.wrightslaw.com](http://www.wrightslaw.com)**

An up-to-date information about special education law and advocacy for children with disabilities.

**[www.fetaweb.com](http://www.fetaweb.com)**

A companion site to wrightslaw.com. Teaches effective advocacy skills. Highlights common pitfalls that prevent parents from successfully advocating for their children's rights.

## **Books And Pamphlets**

*To obtain a copy of these materials, go to the Web site provided. If a publisher is listed, obtain a copy through your local bookstore or library.*

### **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.

#### **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:**

#### **Cancervive Parent's 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 from [www.cancervive.org](http://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, Third Edition: A Guide for Families, Friends, & Caregivers**

by Nancy Keene

Published by O'Reilly & Associates, Inc.

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

by Nancy Keene

Available from [www.candlelighters.org](http://www.candlelighters.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, Inc.

## **Young People With Cancer – A Handbook for Parents**

Available from [www.cancer.gov](http://www.cancer.gov)

## **Videos**

### **Back to School: Teens Prepare for School Re-entry**

Available from [www.starbright.org](http://www.starbright.org)

### **Emily's Story: Back to School After Cancer**

Available from [www.cancervive.org](http://www.cancervive.org)

# Call Our Information Resource Center

The Society's Information Resource Center (IRC) provides patients, families and healthcare professionals with the latest information on leukemia, lymphoma and myeloma. Our information specialists – master's level oncology professionals – are available by phone (800.955.4572) Monday through Friday, 9 am to 6 pm (ET); via email ([infocenter@LLS.org](mailto:infocenter@LLS.org)); or chat online at [www.LLS.org](http://www.LLS.org) (click on "Live Help").

Call 800.955.4572 for a complete directory of our patient services programs.



**The Leukemia &  
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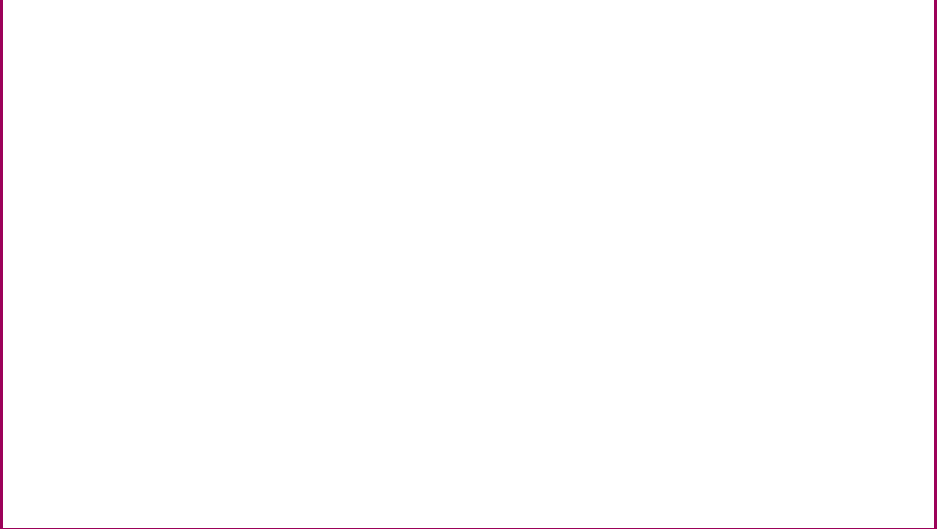
**800.955.4572 • [www.LLS.org](http://www.LLS.org)**

LEUKEMIA

LYMPHOMA

MYELOMA

For more information, please contact:



or:

Home Office

1311 Mamaroneck Avenue

White Plains, NY 10605

Information Resource Center (IRC) 800.955.4572

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

*Our Mission: Cure leukemia, lymphoma,*

*Hodgkin's disease and myeloma, and improve the*

*quality of life of patients and their families.*

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



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