

For more information, please contact:



or:

Home Office

1311 Mamaroneck Avenue, Suite 310

White Plains, NY 10605

Information Resource Center (IRC) 800.955.4572

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 corporate and individual contributions to advance its mission.



**The Leukemia &
Lymphoma Society**®

Fighting Blood Cancers

Emotional Aspects of Childhood Blood Cancers

LEUKEMIA

LYMPHOMA

MYELOMA

*A Handbook
for Parents*



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

Table of Contents

Introduction	2
How To Use This Booklet	4
Part I: You, the Parent	5
The Initial Diagnosis and Emotional Responses	5
New Demands	8
Part II: You and Your Children	14
Talking About the Diagnosis	14
Hospitalization and Clinic Visits	17
Going Home	20
School	21
Camp	26
Brothers and Sisters	27
Part III: Facing the Future	30
When Treatment Ends: Life After Cancer	30
Developmental Issues	34
Meeting Sibling Needs	36
Putting the Illness in Its Place	37
Addressing Concerns About the Possibility of Death	41
If Death Must Come	46
Putting the Family's Life Back in Order	49
Resources for Adults	52
Resources for Children & Teens	53
National Organizations	54

Introduction

In the United States about 12,156 children under the age of 20 are expected to be diagnosed with cancer in 2005. Of these children, about 3,521 will be affected by leukemia and about 1,628 by Hodgkin and other lymphomas. Significant progress has been made in the treatment of childhood blood cancers over the past four decades. Survival rates for children with acute lymphocytic leukemia have improved dramatically. Hodgkin lymphoma now is the most curable childhood cancer. Many survivors have entered the work force, have married, and have had children.

Not every child with leukemia or lymphoma is guaranteed a cure. Progress in some types of leukemia, such as acute or chronic myelogenous leukemia, has been substantial but slow. Children with blood cancers may face years of illness, treatment, treatment-related stress and post-treatment adjustments.

This book is written for parents of young children and adolescents with leukemia or lymphoma who are trying to cope with a most difficult situation. It is for parents who seek support to face and deal with the illness. When parents seek and obtain help to cope with the experience, their children benefit. Although diagnosed with a physical illness, children with these cancers can be in an emotionally healthy environment, and benefit from support for their continued growth and development.

Communication with all the children in the family is equally important. Brothers and sisters of children with leukemia or lymphoma are also affected by the illness. Parents may find that by listening to their other children and giving them ample opportunity to voice their concerns, the family is able to establish a lasting pattern of honesty and openness.

Although aimed primarily at parents of children with leukemia or lymphoma, this booklet is also useful to families with children affected by other cancers. Many parents shared their stories with us. We share their experiences with you, along with the experience of psychologists, psychiatrists, social workers, physicians and nurses who help families deal with the emotional aspects of their child's illness.

Patricia Deasy-Spinetta, M.A., M.S., N.C.S.P.
Psychologist, San Diego Unified School District

John J. Spinetta, Ph.D.
Professor of Psychology, San Diego State University

Faith H. Kung, M.D.
*Associate Professor of Pediatrics, University of California,
San Diego School of Medicine*

The illustrations in this booklet are based on drawings done by children with leukemia and by young survivors of childhood leukemia.

The Society is a nonprofit organization that relies on the generosity of individual and corporate contributors to advance its mission. Call our Information Resource Center for information about leukemia, lymphoma, myeloma treatment, clinical trials, education programs and support services.

How to Use this Booklet

This booklet is divided into three sections. You may choose to read it from start to finish or refer at different times to the sections that address the family's needs.

Part I: You, the Parent

In Part I, we review some of the varied emotions of parents whose children have been diagnosed with leukemia, lymphoma or other cancers. We also discuss some of the new demands placed on you and other family members. Sources of support and assistance are included.

Part II: You and Your Children

Part II discusses how to talk to your children about the diagnosis. To help you become more aware of the impact of cancer on children at different ages and developmental stages, we examine what children understand about their illness. We also talk about hospitalization, family life, school and the needs of siblings.

Part III: Facing the Future

In Part III, we explore issues relating to the completion of treatment. For most families, completing treatment means making the transition to a new phase of life after active treatment ends. For some, it means preparing for a child's death. We discuss the impact of both survivorship and death and offer practical guidance to help prepare you for whatever outcome your family faces.

It is our intention that the information presented on these pages will be helpful to you. We acknowledge that families are different and you may find topics in this booklet that do not apply to your family.

Thinking about your child having leukemia or lymphoma is quite difficult. Most likely, reading this booklet will not be painless. With that in mind, we provide this to help you to address the emotional aspects of your child's illness. We hope the information presented here will support your efforts as parents to deal with the many challenges of your child's illness.

Part I: You, the Parent

The Initial Diagnosis and Emotional Responses

The shock of diagnosis produces a jumble of emotions. Common reactions include confusion, denial, fear, anxiety, anger, guilt, grief and sadness. In addition, your sense of security and your belief in God, or in the meaning of life, may be shaken. Many parents experience these feelings throughout their child's illness. Whatever feelings you experience, as individuals and as parents, are valid reactions to your specific situation.

Shock and Confusion. At the time your physician first talked to you about your child's illness, and perhaps gave a detailed explanation, you may have heard nothing but your child's diagnosis. Just hearing the word "leukemia" or "lymphoma" and learning for the first time that your child has cancer often causes you to block out everything else. Physicians and other treatment team members understand this and you can ask them to repeat information as your questions arise. The information you are given is often very complicated. Some parents take notes or tape 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.

Denial. Most parents want to believe a diagnosis of cancer for their child is a mistake. "The doctor must be wrong." "This cannot happen to my child." "I just will not believe it." For awhile, you may continue to talk as if nothing is wrong. Denial, for a short period of time, may help parents to adjust and shift gears. However, denial about the accuracy of the diagnosis for too long is detrimental to the future well-being of your child and the entire family. It may delay the timely beginning of treatment. Continuous denial isolates and abandons the child at a time of profound need.

Before beginning treatment, some parents seek a second opinion or want to get additional information about the credentials of treating physicians or the medical center. Consultations should be scheduled in a timely manner. Physicians are generally willing to help arrange this.

Hope. Hope is a sustaining human quality and plays an important role in life. As 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.

Fear and Anxiety. The threat to your child's life, and the uncertainty about your child's treatment outcome, are worries common to all parents with a serious illness. You may experience many other fears and worries, including concerns about: 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.

It helps many people to talk about their fears and anxieties. Your child's treatment team includes professionals trained to help you with all aspects of the illness: physical, emotional and financial. Get to know each person on the team, learn how each can help you and enlist their support. They want to help you.

Relatives and friends can be a source of strength and understanding. Some relatives mean well but are not helpful. They may deny the illness, tell countless stories of spontaneous remissions, offer homemade remedies, or frown if you and your spouse take time to be alone. Enlist the help of professionals in dealing with relatives who are not supportive.

Professionals who work with families of children who have leukemia or lymphoma often comment about the ability parents develop to deal with their new reality. Parents discover new and unexpected strengths and strategies for coping.



LEUKEMIA

LYMPHOMA

MYELOMA

Anger. Don't be surprised if you feel very angry at times. Parents with children who are seriously ill say they have experienced anger at being singled out by God or a cruel fate, anger at their child's physician or the entire medical profession for not finding an immediate cure for their child, frustration with the healthcare system and health insurance, anger that their innocent child has to suffer, or even anger at their sick child for becoming ill. 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.

Being able to talk about angry feelings with trusted friends, relatives and professionals is one way parents can learn to accept their feelings. This will help you to keep expressions of misplaced anger to a minimum, and take constructive action when possible. 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. The support given to you by family members, friends or other parents in similar situations is of prime significance.

Guilt. Feelings of guilt are experienced by almost all parents and may be felt for different reasons by each parent. You may think you must have done something horribly wrong and now you are paying for it. You may reflect on your past and dwell on any regrets you have. You may feel responsible for causing your child's illness. You may blame yourself for not paying more attention to your child's symptoms.

Acknowledge and express any feelings of guilt you may have, so that you can get the comfort and support you need. As hard as it is to accept, you may never know what caused your child to have cancer.

Sadness and Grief. You may feel an acute sense of loss the moment the diagnosis is made. This sense of sorrow may deepen as time goes by. You may feel sad that life for your child and family will never be the same. Even though most children diagnosed with leukemia or lymphoma will survive, it is common, at some time during your child's illness, to feel a need to prepare for the time when your child may no longer be here.

While anticipating your child's possible death is normal, it is important to be aware of how premature grief can affect your child. It can make a child feel worried or neglected, or feel the need to somehow protect his or her parents from sadness. Allow yourself to grieve when feelings of loss overwhelm you, but if you feel consumed by these feelings, seek professional help. You must work through your

grief, so that you will be able to focus your energy on giving your child what he or she needs now to make life as complete as possible.

Belief in God or the Meaning of Life. The seeming injustice of your child's illness can cause you to question your views on the meaning, purpose and value of life, or the beliefs you have about God. You may have believed that being good would guarantee that life would be fair for you and your children. What has happened to your child seems so unfair. It is easy to become bitter, cynical or discouraged. These feelings need to be explored. Often with the help of their pastors, ministers or rabbis, parents realize these emotions are not helpful. They try to make the most of their child's life and the time they have together.

The intensity of your emotions may frighten or confuse you. However, your feelings are a necessary part of the entire experience you have with your child's disease and treatment. The feelings you have in the days and weeks following the diagnosis help insulate you from the shock. They give you time to accept and deal with the diagnosis, and to make good decisions regarding medical care. There are many sources of support for you in dealing with these feelings: family, friends, spiritual advisors, your child's treatment team, and other parents. Many parents discover renewed closeness with, and support of, family and friends. A sense of gratitude for "the little things," and a continued belief in the basic goodness and value of life often emerge over time.

New Demands

Theories in physiology and psychology tell us that many untapped energies and skills lie dormant until you really need them. As the parent of a child with leukemia, you will need your untapped resources as you attempt to meet the many new demands placed upon you.

Decision Making. There are immediate medical, family and financial decisions to make. If you have been referred to a large medical institution for complete diagnosis and treatment, you may have to cope with a very sick child in a new hospital, with a new physician, perhaps in an unfamiliar city or town. You need to explain the nature of the illness to your child and find ways to comfort him or her. In addition, you need to help your child to cooperate with medical treatment. You will need to explain what is happening to your other children, answer relatives' questions and perhaps make arrangements about work and childcare. Throughout this experience you will be coming to terms with your own feelings, evaluating the situation, and reevaluating certain choices. None of this is easy.

Disagreements and Compromise. It is common for parents to disagree on important issues. Parents may react differently to the initial diagnosis. You and your spouse may be quite capable of resolving many of the issues related to your child's illness. Given the intensity of emotion and the number of important decisions that need to be made, it is likely you will disagree at times.

Disagreements need to be resolved so you can give your child support. When you cope successfully with the first tasks required to deal with the illness, you lay the foundation for coping successfully with future tasks. On the other hand, if you and your spouse take opposing positions on major issues, you set a pattern for conflict and failure in the future.

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 marriage or are separated or divorced, they need to find a way to set aside conflicts and cooperate in caring for their ill child.

Family members need support from one another. Support starts with the parents and filters down to the children. Trust, honesty and mutual support help a family to function. Any family that is having difficulty resolving differences may benefit from professional help.



Energy Conservation. Children with leukemia and lymphoma may face years of illness, treatment, treatment-related stress and post-treatment adjustments. They also face the prospect of a full and productive lifetime. Parents may have many years of stress with their child, but also many years of joy. It is important, then, for parents to conserve their energies for their child. It is also important that parents support each other, and engage in activities that give them each time for personal rest and relaxation.

This is also an important time to carefully consider the pros and cons of introducing other significant changes into your family's life. Changing jobs, moving, entering into a new marriage, having another baby, and other major life events, may add stress to already overloaded emotional and physical reserves.

Nine months after Laura, age nine, was diagnosed, her mother Marge, who was divorced at the time of Laura's diagnosis, remarried. Initially, Marge's new husband was supportive, but as Laura's illness progressed, he began drinking and leaving home for long periods at a time. Marge found that she could not handle both the stress of her daughter's illness and the added burden of her unhappy marriage. As a result, this marriage ended in separation.

Sometimes, a friend will suggest to a couple that they have another child "to take your mind off things," or "to give you something else to live for." Occasionally, a couple will want a child in order to "replace" their sick child. While we are not suggesting that welcoming a new baby is never right for a family at any time during an ill child's treatment, it is a decision that needs to be considered carefully.

Grandparents/Relatives. Grandparents (and close relatives) may serve as a source of support and understanding for both their children and grandchildren. Grandparents often experience many of the same feelings as the parents of the ill child. In addition, they are concerned for you, their children.

Relatives may also use denial as a way of reducing their own emotional pain. They are hurt and feel threatened by the seriousness of the illness. You may find yourself not only having to come to terms with your own grief, but also feeling the need be a source of emotional support for grieving grandparents and relatives. You may find it helpful to talk to other parents and members of the treatment team for support in sorting out your priorities.

Relatives who live a distance from the treatment location may challenge the reality of the diagnosis. They want to know if the physician is certain of the diagnosis and outcome. They may suggest that parents go elsewhere for better treatment or that they seek faith healers. Parents who are desperately trying to cope with their own emotions must often endure the well-intentioned suggestions of relatives.

Normalcy in Family Life. Probably the most essential, demanding task facing parents is maintaining a normal family life. A child with leukemia or lymphoma continues to achieve, develop and grow. To overcompensate for the illness by showering your child with gifts or by abandoning all previous forms of discipline is confusing to a child. It may make brothers and sisters resentful. The case of Raul, age 6, is an example of overprotection and its consequences.

Raul lived with his parents and two brothers, ages 4 and 2. His mother believed her sick child needed all her attention. She showered him with gifts, kept him home from school, took him on special outings without her husband or other sons. Whenever he was hospitalized, his mother spent the entire time with him and would not let her husband relieve her. Raul became manipulative and demanding. In the hospital he fought all medical procedures and at home he demanded and got everything he wanted. His two brothers, not understanding the situation and resenting the special attention Raul received, became disciplinary problems in their own way. Raul's father disliked coming home. He could not communicate with his wife and his three sons were out of control. This family, because of well-intentioned but mistaken notions, allowed the disease to split them apart.

Mandy's story demonstrates how important it is to set rules for a sick child and maintain discipline and normalcy in the home.

When Mandy was diagnosed with leukemia, her parents talked with her healthcare team. They were encouraged to set some limits for Mandy, as they did before she got ill. Mandy's mother and father set clear rules for the household. They expected Mandy to follow these rules, as much as she was physically able. To maintain standards of discipline, Mandy's mom asked herself, "What would I have done in this situation before Mandy had cancer?" Setting limits in the home was reassuring to Mandy and offered normalcy in her world, which had changed dramatically when she was diagnosed. Mandy got the message that she was expected to follow the rules. Mandy felt that her parents expected her to get well, grow up and continue to be a responsible member of the family.

Marital Strain. Caring for a sick child can strain a marriage. Even when both partners take a unified approach to caring for their sick child, and to maintaining open communication within the family, there can still be occasional strain. One reason for this is that each partner in a marriage is an individual with his or her own way of expressing emotion. One spouse might find great relief in crying and the other may not cry at all.

One couple, Anne and Fred, had very different styles for expressing their emotions. Fred cried himself to sleep for many nights after learning about his daughter's diagnosis. Anne did not cry. She found herself eating more than she normally did. Fred accused Anne of being hard and cold for not crying. It took time and honest communication for them to realize that both were hurting deeply, and that it was not necessary for them to grieve the same way. With this understanding, they were able to support each other and accept each other's style of expression.

It is not unusual during the illness for a parent to desire increased attention and comfort from his or her spouse. When this is mutual, it is a source of closeness, warmth and support. When it is not, it can create conflict. One parent's need for affection may cause his or her partner to think, "How can you think of something like that at a time like this?"

Conflict between parents, whatever the reason, is sensed by their children. Communication between parents is important, so that conflicts are resolved before they begin to interfere with the functioning of the family.

Pre-Illness Problems. When the family of a child with leukemia or lymphoma is already strained by marital, alcohol, drug, mental health, financial or legal problems, the child's diagnosis may seem like just one more blow. If this describes your family, for your child's welfare, it is most important for you to seek professional help. The added stress of diagnosis, treatment and long-term care of the sick child or adolescent is often too much for even the strongest family to bear without some outside support.

Sources of Support. As parents prepare to meet the new demands of their child's illness, it is wise for them to take an inventory of sources of support. It might be good to look back and analyze who or what has helped in the past.

A group of parents whose children had leukemia and lymphoma were asked to list their sources of support during the long haul of their child's illness. Their lists included: spouse or significant other, counselors, the sick child and other parents of sick children.

The strongest source of support seems to have been the presence of an understanding spouse or significant other or a close friend to turn to as problems arose. The spouse was not a supportive factor in all of the marriages. Some people turned to friends because they accepted that they could not get the support they needed from their spouse.

The hospital staff was of assistance to many families. Parents as a whole had great respect for the competence of their physicians and other treatment team members. Parents appreciated the doctors', nurses' and social workers' understanding and sensitive care of their child.

Religion was a powerful factor in the lives of many parents who had a strong religious belief prior to the diagnosis. Some of their comments were: "My religion and faith in God helped me the most." "I believe in God and derive strength in this belief."

It is not unusual for parents to derive strength from their own sick child.

Alice, Shannon's mother, said, "I kept myself going when I saw how well Shannon handled herself in stressful situations."

Finally, parents find other parents with sick children a source of support. Parents of children with cancers are a special 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 have gotten to know each other while their children were hospitalized or in the clinic. Some have organized or joined parent support groups that meet on a regular basis. These contacts help parents cope with many aspects of the diagnosis, treatment, family and work life.

Goals. In this section we talked about the demands placed on families who have a child with leukemia or lymphoma. Not all of these problems are faced by every family; however, knowledge of potential areas of stress can be very helpful.

Medical goals are clearly defined by your physician and involve the best possible care for your child. What about psychological goals? What is your goal for your child? What is your goal for your child's quality of life? What about your goals for your other children? Will the suffering of a brother or sister frighten your other children? What about yourself? Will you let this illness fragment you? What are your goals for your marriage? Will the illness be a cause of deeper love, respect and trust?

Part II: You and Your Children

Most likely you are concerned about what your child knows about his or her illness, treatment and their consequences. This is not an easy subject to face. In this section we will share current findings to guide you in understanding and answering your children's questions.

Talking About the Diagnosis

Experts recommend talking to your child or adolescent about the seriousness of his or her illness at the time the diagnosis is made. Depending on the age of the child or adolescent, patients should be included in discussions about diagnosis, treatment and prognosis whenever possible. It is harder, in some ways, to talk to younger children about these issues. However, children who are old enough to ask questions are aware of cues in their environment that something is different. Honest information, presented in simple, age-appropriate terms supports their ability to trust you. It encourages your child or adolescent to ask questions about what is happening to them. This gives you the opportunity to be aware of and address their perceptions about what is happening and why. It helps decrease some of your child's fears. Energy that would be wasted maintaining deception can be applied to the real problems of living with a life-threatening illness.

With recent medical changes increasing the life span of many children with leukemia and lymphoma, healthcare professionals tend to respond to children's questions early in the course of the illness with a reality-based optimism. Parents and children are encouraged to keep their hopes alive. Anytime a child or adolescent reveals fears, concerns or fantasies about his or her illness or experience with treatment, it is important to listen and respond honestly to his or her concerns in age-appropriate terms. Adolescents often keep what they know or suspect to themselves, or do not always want to talk with parents about their fears. Sometimes this is because they are afraid of upsetting their parents.

While hope of cure should be maintained, it is unrealistic to think that a child over 4 or 5 years of age can be kept unaware indefinitely of the potential fatal nature of his or her illness. When the diagnosis and seriousness of the illness have not been shared honestly with a child, the child generally does not reveal his or her fears about death, or other fantasies about what is happening. A child's fears and concerns, or fantasies that are not addressed openly may lead to a loss of hope, optimism and good quality of life.

Telling your child or adolescent about his or her diagnosis, treatment regimen and potentially shortened life span is a difficult and complex topic. It cannot be done casually or in a single session. (For a further discussion, see the section, *Addressing Concerns about the Possibility of Death*.)

Infants, Toddlers and Preschoolers. Studies of seriously ill children less than five years old indicate that fears of separation, abandonment and loneliness are most pressing to them. These children look for comfort from their primary caregivers. At an age when most children are especially involved with magic, they see parents as magical beings that can make illness and discomforts go away.

Early School Years. From the ages of 6 to 10 and perhaps as young as 5, children have fears related to physical injury and bodily harm. The fear of abandonment is replaced by a fear of bodily harm. Children in this age group often feel powerful in causing illness. They may view illness as punishment for their thoughts and actions. Often they may feel that saying or thinking bad thoughts caused their disease or made them ill.

Studies of children with leukemia in this age group reveal that, despite efforts by parents and medical personnel to conceal the truth, the children somehow sense the seriousness of their illness. Younger children often try to “protect” their parents by not letting them know how much they really do understand about their illness. Perhaps the loneliest of all, are those children who are aware of their diagnosis but recognize that their parents do not want them to know. As a result there is little meaningful communication; there is no one with whom the child can openly express his feelings of sadness, fear or anxiety.

Ruth and Harry were confident that they had succeeded in keeping all knowledge of her illness from their 6-year-old daughter, Lucy. A psychologist showed Lucy a picture and asked her to tell him a story about what was happening in the picture. The child said, “The little girl in the picture is very sick in the hospital. The

girl's mommy and daddy are talking to the doctor at the door. The doctor is telling the mommy and daddy that the little girl is very, very sick. But the girl is pretending to be asleep, because she doesn't want her mommy to know that she knows how sick she is. Because then her mommy will cry."

Preadolescent and Adolescent Years. Children over 10 show a fear of illness and death. In the preadolescent and adolescent, this fear takes precedence over other fears. They become aware of the seriousness of their illness. This awareness, if coupled with a lack of meaningful communication by adults, can cause children to worry even more. Children in this age group become especially worried when confronted by a conspiracy of silence and find great relief when given an opportunity to discuss their concerns with a sympathetic adult.

It is important for parents to talk to their child about the diagnosis. Children usually sense it anyway, and can understand their illness. Therefore, they should be told, and need to be included in discussions about their health and their healthcare. In this way you let children know that their concerns are shared and understood, and that you are willing to talk about these concerns. Also, it is important to remember that your child's worries about the possible outcome of his or her illness may be different from your concerns as parents. With the onset of puberty, preadolescents and adolescents are very focused on their bodies and concerned about the changes taking place. Adolescents sometimes have issues about the impact of treatment on their sexuality and their ability to have children in the future. They may prefer to discuss these concerns with physicians or other team members.

Children and adolescents build defenses to protect themselves from too much emotional pain, but they also want to be told the truth. It is a challenge to understand and respect your child's defenses, and at the same time to be honest and open to questions asked about illness or death. Meeting this challenge with love, intelligence, understanding, and compassion will greatly enhance your child's quality of life.

In summary, we can say that the anxiety of the seriously ill child under age 5 takes the form of fear of abandonment, separation and loneliness. The child between ages 6 and 10 senses that this is no ordinary illness, and that it is serious. At this age, a child is fearful of bodily intrusion, pain and harm. Since preadolescents and adolescents are usually aware of the possible life-threatening nature of their illness, they can be very anxious about the possibility of death. Children and adolescents gain this awareness despite any efforts to keep them from knowing their prognosis. They should be allowed every opportunity to talk about their concerns.

Updating Knowledge. As children grow, their capacity to understand grows too. With their ability to grasp more about life in general, there is a desire to know more about their illness. To tell a child once, at age 5 or 6, about his or her illness is not enough. You need to have ongoing discussions that evolve as the child matures.

Most hematologists-oncologists who treat children speak to the parents when the child is present. This is a good idea that builds trust. If the child or adolescent always takes part in decisions regarding the illness, then his or her knowledge and understanding remain accurate and up-to-date.

Hospitalization and Clinic Visits

Treatment of young people with leukemia and lymphoma takes place in many healthcare settings: medical centers' inpatient floors and outpatient clinics, offices of local pediatricians and family medicine practitioners and in the home, with assistance from home health workers.

A child enters a new world when admitted to the hospital. It is a world of strange machines and unfamiliar routines. As the child becomes aware of other patients and their conditions, he or she strives to make some kind of order out of the surrounding confusion. Most medical centers will be prepared to orient children and adolescents to all aspects of their hospital experience and to assist parents in preparing children and adolescents for different treatments and events. Child life workers, lay therapists, social workers and psychologists may be involved in this process. From the beginning, it is important to encourage your child to express all concerns, and for you to seek out someone on the treatment team who will answer questions in language your child understands. Honest communication on all subjects will free much of the child's emotional energy from struggling with unknowns. Energy then can be used to deal with everyday problems.

The Younger Child. Hospitalization can be a traumatic experience for an infant, toddler or preschooler, especially if the child is separated from his or her parents. You can lessen trauma by staying with your child. "Sneaking away" may increase the separation anxiety. If you do need to be separated from your child for a time it is better to explain this in advance. Understanding nurses are not a substitute for you.

You may notice that your young child resumes behaviors from an earlier stage in his or her development while hospitalized. This is normal.

Immobility and Negative Feelings. Hospitalization usually involves some restriction of movement for a child. Difficult medical procedures, administered by a steady stream of unfamiliar people, can contribute to many negative feelings. Tension builds; the child sometimes becomes anxious and unruly. The hospitalized child needs an explanation of the medical procedures and also allowed freedom to play.

The Playroom. Children use play to relax and have fun. It helps them to cope with their feelings about hospital equipment and medical procedures and personnel. At many hospitals, playrooms are an important part of the children's cancer program. These playrooms are designed to foster natural and spontaneous play. They provide opportunities for children to ask questions and act out concerns. Play therapists can visit bedridden patients to achieve these same goals.

In some hospitals healthy brothers and sisters can join play activities, usually in the outpatient clinic. Familiarity with medical equipment and hospital staff helps relieve their anxiety regarding the welfare of their sibling.

Playroom staff are trained professionals with backgrounds in psychology, special education, early childhood education, social work, occupational therapy, nursing or recreational therapy. They are an integral part of the team caring for your child. Play therapists are in a position to evaluate what your child may be dealing with at any given time, such as resistance to medical procedures, fear, or passivity.

Kerry, age 6, drew pictures of four adults, all drawn as monsters. He explained that one was doctor, the other was nurse, the other was mom, and the last one was dad. He said he was very mad at mom and dad for letting the doctor and nurse do all these horrible things to him. Paul, age 5, found a favorite toy, the doctor doll. He pounded that doll each time he came into the room. After releasing his emotions, he relaxed and continued with his art work or puzzle.

Expressions of Anger. Children often become angry with the people who administer treatment. They can also become angry with parents for allowing painful or frightening procedures. It is not unusual for some to actively rebel against treatment. Younger children sometimes openly reject parents, making such statements as, "I don't ever want to see you again." "I hate you." "Why do you let this happen?" These statements usually come after a long period of hospitalization during which the child undergoes many medical procedures. Children believe in parent-power. Some of a child's faith in parent-power is shaken when mom and dad are unable to prevent these procedures. Some researchers speculate that young children and adolescents,

sensing their dependence on nurses and doctors, are fearful of expressing anger directly at them, so they let it all out on their parents. Adolescents may present some special challenges in this regard.

The Older Child. Hospitalization threatens a child's progress towards independence. The child who is taken to the doctor, taken to the hospital and given treatment becomes a passive recipient rather than an active participant. When an effort is made to provide an explanation that is appropriate for the child's level of development, the child is able to understand that continuous hospital and clinic visits are necessary to control the disease and maintain health. This open communication helps promote cooperative behavior in spite of the infringement on the child's independence. The child who is old enough to understand some of the implications of his illness, but is told nothing, can become rebellious.

The Adolescent. The lack of independence resulting from hospitalization is particularly displeasing to the adolescent. In Doris Lund's book, *Eric*, 17-year-old Eric refused to allow his mother to accompany him to the clinic or participate in discussions with the doctor. As difficult as this was for her, Eric's mother respected his need to exert as much control as possible over his leukemia.

Diagnostic and Therapeutic Procedures. Some parents feel better if they can remain with the child during treatment. Others are relieved when they are not expected to be present. Single parents usually bear most of the physical and emotional burden of clinic visits. When both parents are involved, they must decide who will go to the clinic according to what works best for the whole family. When possible, it can be worth it to adjust work schedules so that both parents may share clinic visits.

Death on the Pediatric Ward. Occasionally, a child is hospitalized when another child on the ward dies. There is then a noticeable change on the ward. There may be a flurry of activity as hospital staff gather. Frequently, parents are seen crying. The child who witnesses this activity may even know, from clinic visits and playroom activities, the parents and the child who has died. Adults may strain to keep knowledge of the death from the other children in the ward. But the children are aware that something has happened and are doubly attentive for clues to explain it. The situation is emotionally trying for the parents and children. It must be handled as circumstances dictate, but parents should be sensitive to their own child's needs for understanding, reassurance and reaffirmation of hope.

Going Home

Parents and children look forward to the day the child will be well enough to be discharged from the hospital. Yet, some parents fear that an acute medical problem may arise that they will be unable to handle. If you have these concerns, discuss them with your child's treatment team.

Discipline. Establishing normalcy in the home is a basic task facing parents at all stages of their child's illness. Often parents feel they should pamper a child who is sick. In reality, children want to be thought of, and treated as, normal and become fearful when they seem to have too much power in getting their own way.

A pampered child is quick to take advantage of an atmosphere of permissiveness, and brothers and sisters may become resentful. Children, even young ones, begin to test limits as soon as they return from the hospital.

Lori, age 11, announced to her three brothers that she could do anything she wanted and they could not as much as touch her, because if they did she would bleed to death and they would be responsible. Fortunately, Elana, Lori's mother, heard the conversation and told Lori she had duties and responsibilities, as always, just like her brothers. Elana needed to reinforce this concept from time to time. In doing so, the entire family benefited.

It is not unusual for some parents, or well-intentioned grandparents, relatives and friends to shower a child with presents.

Kevin, age 15, recalls, "I knew I was really sick when dad bought me a dirt bike. I had wanted one for several years and dad had said, Absolutely not! Then, two days after I came home from the hospital, there was the bike. That made me feel terrible."

Healthy brothers and sisters are quick to sense that there is something seriously wrong, whether or not they are told directly by their parents. Knowing something is wrong, they will make certain allowances. Older children usually enjoy a family outing geared towards the wishes of the sick child, but they should not be expected to tolerate constant overindulgence.

Overprotection. When your child leaves the hospital, your physician will provide specific instructions about any limits to your child's activity. Address any concerns or

questions you may have about the advice you receive. Some parents add their own, far more limiting, ground rules. Your fears may include activities that might tire your child, or activities that might cause bruising. Emphasize what your child can do, rather than what your child cannot do. Encourage school attendance and participation in school activities, as long as it is okay with your child's physician. This is an area of disagreement between some parents. Keep your child's quality of life in mind and seek professional advice when needed.

School

With current treatment, children with leukemia and lymphoma spend less time in the hospital and more time at home and school. Going to school enables these children to fulfill their potential for growth and development. Participation in the regular classroom takes on added significance as a normalizing factor in the life of a child after hospitalization.

Communication among Home, Hospital and School. It is important, then, to maximize the child's ability to succeed in school; this takes communication among home, hospital and school. Many serious childhood diseases are burdened by mythical concepts. Communication with the school is necessary to dispel the myths and to give accurate, child-specific and age-appropriate information.

It is not enough for a parent or clinic nurse to tell the school that the child has leukemia or lymphoma. Each case is individual; each child's stage of illness or recovery differs. Teachers need to know if the disease could affect the child in the classroom, and how to deal with any such effects. Teachers also need to be informed about any effects of treatment on the child's learning abilities.

In preparation for your child's return to school, you may want to schedule a meeting with teachers and other appropriate school staff to provide information about your child's illness and treatment, and to plan for your child's return to the classroom and school activities. You may be able to arrange for a member of your child's treatment team to be a part of the conference. Many medical centers are prepared to have hospital-based teachers assist with this. When this is not possible, parents can convey the necessary information, make use of resource materials, and refer any questions or concerns to the healthcare professional assisting with school re-entry issues.

With your child's agreement and support, a classroom presentation may be part of the plan to help classmates understand your child's situation. Frequently, children

attend class with some visible signs of their illness. Treatment side effects like hair loss and weight gain can be explained. This will help your child to maintain self-esteem and gain peer-acceptance. Avoid explanations that, while medically accurate, set your child apart.

Optimally, one or both parents, and a representative from the treatment team, should attend the classroom presentation, along with the child. When healthcare professionals cannot make a school visit, the teacher, child, and parents can collaborate on the presentation. Information for teachers and videotapes for making classroom presentations are available through The Leukemia & Lymphoma Society. When planning a return to school, the special needs of middle and high school students, who generally have several teachers, need to be considered.

Your goal is to have your child viewed as a student dealing with a serious illness, not as a patient who happens to be in school. School provides a haven where the child or adolescent can be free of the cares and concerns of the hospital or clinic.

Teachers are People. It is important that your child is viewed as a student and not as a patient; it is equally important to realize that your child's teacher is an educator, not a healthcare professional. School personnel should be clearly advised that your the child is under a physician's care and is seen regularly.

When the physician or clinic nurse or hospital teacher are available to answer the questions of school personnel and to offer assistance when needed, the anxiety of the teacher regarding medical concerns is reduced. However, if the teacher, school nurse and other involved school personnel do not get adequate medical information and support from parents and the child's healthcare professionals, they tend to view their responsibility as primarily medical, and they view the student as a patient. The result is a school situation that does not maximize the student's potential for success.

The presence of a child with a potentially life-threatening illness in the class can arouse many emotions, fears, and anxieties in the teacher. Commonly, teachers overprotect the child. This is a normal human reaction. It is important for the teacher to have the opportunity to discuss these feelings with someone. Frequently, school personnel will not discuss their feelings directly with parents because they do not want to cause them further concern. Healthcare professionals dealing with the child can contact school personnel and give them the opportunity to express feelings and obtain additional information.

Specific School Problems. Research has demonstrated that children with leukemia or lymphoma enjoy school: they interact with peers and they continue developing skills. However, young people with serious illnesses do have their own set of problems. Absences can be a major road block to academic achievement. Parents and educators must do everything possible to minimize the negative effects of absences.

Sometimes a child or adolescent is reluctant to return to school after the initial diagnosis or after hair loss occurs. When your physician determines that your child is medically ready to return to school, then you and your child can work with teachers to plan for a smooth return. Often, after a short time, children and adolescents gets caught up in their school world and do fine.

You may want to explore the different services available in your school district to help your child. For example, special tutoring programs are very helpful in assisting children with schoolwork. Remedial programs are also available and may be helpful to returning students. With you and the school viewing your child or adolescent as a growing, developing person with a future, creative education plans that support your child can be put in place.

Some children may suffer late effects of treatment that affect cognitive and academic functioning. These children are eligible under the Individuals with Disabilities Education Act (IDEA) to receive special education services. Parents and hospital staff can work with school personnel to identify any learning disabilities. An Individual Education Plan (IEP) can be developed to meet any special needs your child or adolescent may have. Many children and adolescents who require special education services are able to continue to function in the regular classroom, but may benefit from modifications and accommodations to the regular curriculum, which they are entitled through the Americans with Disabilities Act, Section 504.

Adolescent Student/Patients. Adolescents need to assume an active role in their education. Graduation and college entrance requirements can be met in spite of all the absences necessitated by treatment and illness. High school students, their counselors and teachers can work out a flexible schedule that both meets class requirements and allows for medical needs.

Bill was a high school senior who was hospitalized every four weeks for seven days of treatment. The consequences of these lengthy absences could have been devastating, both academically and psychologically, if he had not taken appropriate steps to inform the school. Each semester an initial contact was made with the school counselor by the educational liaison at the hospital. The counselor and Bill met with all of his teachers and worked out a 504 plan. Attendance requirements were waived and makeup tests were guaranteed. Bill graduated in the top 20 percent of his class and was accepted at his first-choice college.

Bill adopted a “can-do” attitude and was able to take the necessary steps for academic success. It was not easy for him. He dreaded facing all his teachers. But he did it, and in doing so gained valuable experience overcoming obstacles that life often presents.

Joyce refused to tell anyone at her large high school that she had leukemia. Absences mounted, work was incomplete and failure notices were sent home. Frustrated and angry, she dropped out of school.

Joyce came for medical care but tried to deny any effects her illness could have on other aspects of her life. Because she did not get guidance on how to face the consequences of her illness she did not have the same success as Bill.

As a parent, it is important for you to recognize that some adolescents are self-starters, while others need more guidance. Assess your adolescents’ needs and give them the assistance and independence they need to help ensure future success.

Nursery and Preschool. If you are the parent of a preschool-age child with leukemia or lymphoma, you may wonder about sending your child to preschool during the treatment phase of the illness. Some families have done this with positive results for the child and other family members.

First, preschool gives the child an opportunity to play with other children and participate in many worthwhile and enjoyable learning experiences. It also helps the child develop a sense of independence.

Second, preschool gives the child the assurance that mommy or daddy always comes back. This assurance may transfer to the hospital setting and permit the child to tolerate short parental absences.

Third, preschool enables the child to master age-appropriate developmental skills. Many young children with serious illnesses are overprotected by parents. They are not allowed some of the activities engaged in by peers because of the fear of injury. When these children enter kindergarten they are often developmentally delayed and are unable to master kindergarten requirements. Preschool enables the child with leukemia or lymphoma to develop age-appropriate skills. Preschool teachers can also assist parents in helping their children acquire these skills at home.

Finally, preschool allows the parent to have some special time with a younger or older child or to spend a few hours alone. The strain of coping with a child with a serious illness is very draining. One young mother admitted that it was these short respites while her little girl was in nursery school that enabled her to regroup her forces and continue with daily life tasks.

Preschool can have a positive role in the young child's quest to live a full and meaningful life.

Siblings and School. It is not unusual for a brother or sister to be cooperative and supportive at home and then act out in school. You may also wish to check with the school regarding your healthy children.



Rick was a 6'2", 185-pound sophomore who periodically engaged in childish behavior. He was not malicious, and never hurt anyone, but he created such a disturbance that it was impossible to conduct class. During a parent conference following one of these incidents, Rick's parents told the teacher and Vice Principal that their 17-year old daughter had leukemia and was recently hospitalized. A review of the records showed that Rick had been sent out of class each time his sister was hospitalized. The parents realized that this was no coincidence. Rick was cooperative at home, especially when his sister was sick, but he let out all his anger and frustration at school.

Summary. Today greater numbers of children and adolescents with blood cancers are cured or are living longer. Current treatment options also help them to have more normal lives by attending school. For these reasons, communication with the school becomes not a luxury but an essential element in the total care of the child.

Everyone benefits from expanded communication with the child's school: the child is happier in school; the needs of the siblings are recognized; teachers are more comfortable in their roles; the parents are content that the child is safe, productive and functioning like other children his or her age; and the physician obtains a more complete picture of the child. Teachers and other school personnel play a significant role in the life of the child. Given adequate preparation, information and support, they play a valuable part in the total care of the child.

School, then, takes on a great significance as a normalizing factor in the life of the sick child.

Camp

Residential camping programs geared to children with cancer can be a wonderful experience for children and their families. The opportunity to take part in traditional camp activities can enrich a child's quality of life, boost self-esteem, and offer a welcome respite from the stress of living with cancer. Like school, camp satisfies the child's desire to do normal things. And camp offers an added benefit by providing a supportive setting filled with peers and adults who understand and share the child's concerns. The camp experience thus fosters the development of strong bonds and enduring friendships that can mean the world to a child who feels isolated or different.

Some camps are exclusively for children diagnosed with cancer. Others accept children with many kinds of physical disabilities or serious illnesses, including cancer. Most resident or sleep-away camps offer one- or two-week sessions that are provided for free or at very low cost.

Not every camp is suitable for your child. While all camps provide medical supervision and support, some are better equipped to meet the needs of campers who are undergoing active treatment or are terminally ill. Others may provide greater accessibility for campers with physical disabilities. In choosing a camp, ask about the physical layout, onsite medical facilities and staff, and the ratio of adult staff and volunteers to campers. Be sure to describe any special requirements your child may have and find out whether the camp can accommodate them.

It is also important to consider your child's particular interests. Evaluate the program activities offered. Are they broad enough to appeal to your child? Does the camp encourage children to develop new skills, but also allow for some flexibility in choosing activities they enjoy best? How are activities modified to insure full participation regardless of disability?

A number of camps sponsor sessions for siblings. Led by specially-trained staff, these programs can be extremely beneficial, especially for siblings who have had a great deal of difficulty coping with their brother's or sister's illness. These sessions can also significantly improve siblings' knowledge and understanding of cancer by giving them age-appropriate information about the disease and its treatment.

For additional information or referrals to camps for children with cancer, contact the American Camp Association (800-428-2267) or the American Cancer Society (800-ACS-2345).

Brothers and Sisters

Brothers and sisters may be confused and frightened by their parents' sorrow and their own inability to comfort their parents. At the beginning it is sufficient to tell all family members that the ill child has a serious illness that will require regular medical care. The children need to know that the disease is not contagious. They also need to know that they are in no way responsible for their brother's or sister's illness.

Brothers and sisters have their own problems: headaches, bedwetting, poor school performance, school phobia, depression, anxiety and stomachaches. They resent the

extra time parents must spend with the sick child. Some children actually feel angry that their parents allowed this to happen to a brother or sister. They may be preoccupied with fantasies about death. These children's needs are real and require attention. Your child's treatment team can make helpful suggestions.

Children, even young ones, are sensitive to what is happening. They are aware of a brother's or sister's hospitalization, and of trips to the doctor and clinic. They notice dad crying and mom trying to comfort him. They may overhear parts of conversations that are difficult to understand.

Children often conspire to figure out what is going on. Pieces of information are gathered, pooled and analyzed. If the children ask and are put off, they will become hurt and mistrustful. These feelings can be lasting.

Lars was age 7 when his sister died of leukemia. He was never told that she was sick, and when she died he was sent away to live with a relative. After the funeral he returned home to find his sister gone and his parents in a state of grief. No explanation was offered and Lars was convinced he had done something that caused his sister's death.

He carried this burden of guilt until he was 15. He had many problems at school. His math and reading remained at about a second grade-level. His parents were concerned and cooperative, but were not able to identify the problem. After leukemia was discussed in a health science class, Lars hesitantly told the teacher his story. He wanted to believe that he was not responsible for his sister's death, but he needed to hear it directly from his parents. A conference was set up, and with the support of his teacher, Lars told his parents his feelings of guilt. The parents were astonished. They had no idea their son felt any responsibility. Through many tears, they told him the entire story and tried to reassure him that in no way was he responsible. In fact, he had been a source of comfort and support to both his sister and his parents.

The following story offers examples of how parents may help brothers and sisters adjust positively.

When her brother Jerry came home from the hospital, 12-year-old Cindy became silent and withdrawn. She no longer participated in school activities and at home she fought with her brother and ignored his visitors. She was envious that Jerry received more attention from family and visitors. Concerned about how Cindy was feeling, her mother and father found the time to meet with a hospital counselor. Shortly thereafter, they started family meetings on a regular basis to keep the lines of communication open. During a meeting, they acknowledged what a stressful time it was for everyone. They talked openly about what was most difficult for each member of the family.

Cindy talked about her disappointment that things at home did not revert to normal or even seem to improve with her brother's return from the hospital. They discussed all aspects of her brother's illness and recovery and why his needs sometimes must come first. They explained to Cindy that they would be unable to meet some of her needs, but did not care any less about her than her brother. An atmosphere of mutual support and understanding was established and the meetings continued every week; more often if needed. Cindy became a happier child and was glad her brother was home.

At times it is hard to remember how much brothers and sisters love one another, especially when they are fighting. But when a serious problem arises they are usually genuinely concerned. This concern shows itself in different ways. In one family, the 15-year-old son was greatly concerned about his mother's well-being. "Mom, you look so worried. You have so much to do; you look so tired." His 9-year-old sister, in contrast, had fantasies about the "scary" medical treatment her 5-year-old sister was receiving at the hospital. She became physically ill every time her little sister went to the clinic. One day the mother took the 9-year-old with her to the clinic to show her what took place there. The reality of the clinic visit went a long way in allaying the fears and fantasies of the concerned older sister.

Children faced with a serious illness in the family need all the support a parent can give. This support must be continuous and must extend for years. As children grow and develop, their understanding of the illness changes, and with it, their questions. It is a delicate task for parents to recognize these changes and answer questions at each of their children's level of understanding.

Part III: Facing the Future

There are many potential problems and stresses a family must face in adjusting to the time when treatment ends. Coping with the shock of the diagnosis, the pain and anxiety of treatment, and the disruption of daily life requires a boundless reservoir of energy. Now, the focus changes again. For most families, the end of active treatment leads to a cure. For some, sadly, it ends in death. Regardless of the outcome, you have shown tremendous strength, courage and compassion.

The next sections of this booklet deal with adjusting to life after active treatment ends and to preparing for a child's death.

When Treatment Ends: Life after Cancer

Every parent of a seriously ill child longs to see the child make a full and complete recovery. It bears repeating that most children who are treated for leukemia or lymphoma survive. For these children and their families, the end of treatment marks the beginning of a new phase in the journey to recovery. And even though families hope for the day when their child will be ready to go off therapy, making the transition to survivorship is not easy.

Adjusting to life after treatment requires some major changes in your family's roles, relationships and routines. This section explores some of the complicated emotions that may arise when active treatment ends. We will also discuss strategies that can help ease the adjustment for everyone in your family.

The Anxiety of Separation. For months or years, your family's life has revolved around treatment. Although it was an ordeal, you eventually adjusted to the seemingly endless round of clinic visits and hospitalizations. Through the relationships you developed with your child's treatment team, various healthcare providers and other families coping with childhood cancer, you became part of a community of support, understanding and reassurance.

Most families are ambivalent about ending treatment. On one hand, you and your child are delighted to be done with difficult procedures. On the other hand, you feel sad and anxious about separating from people who have become very important to you. Even though you and your child may look forward to reunions with the treatment team during follow-up visits, you may find that your anxiety about returning



for check-ups prevents you from enjoying these visits as much as you thought you would. You may also feel conflicted about maintaining your attachment to the other families you became friends with during treatment. While some parents choose to remain involved with families whose children are still in treatment, others feel a need to sever these ties. Children may also feel different than their parents about staying in touch with the people they met while in treatment. It is important to consider the feelings of everyone in your family. Give yourself permission to do what feels right to you.

Fear of Recurrence. People often describe treatment as a “safety net,” a “security blanket” or an “umbrella.” Like many families, you may come to feel that treatment – as grueling as it is – offers a kind of magical protection to your child. When the safety net is pulled away, you feel vulnerable. And if your child has lingering health problems as a result of cancer treatment, it is impossible to simply “put the experience behind you” when active treatment ends.

For survivors and their families, hope and fear go hand-in-hand. When your child completes treatment and is given a cancer-free bill of health, you have every reason to be hopeful. But given the uncertainty of remission and the long-term effects of treatment, there is no way to completely free your mind of fear. Unfortunately, this is part of the legacy of childhood cancer. No matter how positive your attitude, how strong your faith, or how excellent the prognosis, survivor families have to learn to manage the fear of recurrence. There may also be ongoing medical concerns, such as learning problems, that need to be addressed. For more information, see The

Leukemia & Lymphoma Society's Fact Sheet, *Long-Term and Late Effects of Blood Cancers*. You may find that there are times when your anxiety is heightened, for example, during routine follow-up visits or whenever your child runs a fever, gets a cold or becomes more fatigued than usual. Even the most minor complaints can arouse an acute sense of anxiety. Many parents in this situation feel like they are overreacting, but in fact, there is a very real trigger for the anxiety. It is understandable to become unnerved when you are reminded of the symptoms that preceded your child's diagnosis. The best way to deal with these worries is to acknowledge them. Express your fears to your child's physician. If symptoms are worrisome, make an appointment to have your child examined. Similarly, if your child seems anxious or has questions about the future, be responsive. Encourage your child to express any fears and concerns and answer questions as honestly as you can. Over time these fears usually diminish.

Resistance to Change. When treatment ends, many families find it difficult to shift gears and reorient themselves to life beyond treatment. In order to comply with the strict protocol of active treatment, families must allow cancer concerns to take center stage. Other interests and pursuits are put on hold as parents strive to deal with treatment. The focus on getting through treatment provides the order and structure the family needs to deal with a potentially life-threatening illness. That may be one reason why it is so difficult to “switch gears” when the acute phase of treatment ends.

Another reason why families continue to remain organized around the illness is that the patient and the primary caregiver are reluctant to sever the intense bond they formed during active treatment. In most families, it is the mother who fulfills the role of primary caregiver. And despite the enormous sacrifices and emotional burden of the job, “being there” for your child can be tremendously gratifying. Indeed, the degree of dependence feels so comfortable that both mother and child find it hard to give up their roles. However, if this intense relationship persists beyond the time it is necessary other family relationships may be jeopardized. In adapting to life after active treatment ends, patient and caregiver must find a way to restore the appropriate balance in their relationship with each other and the other members of their family.

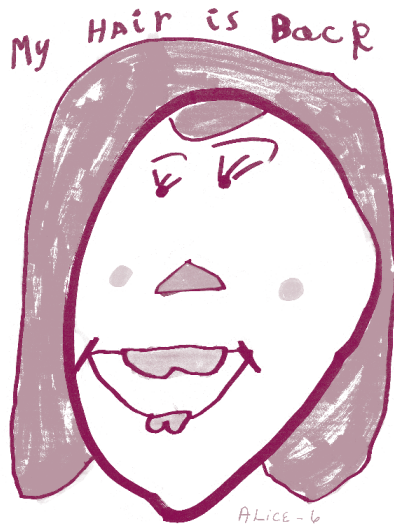
Overprotection. While a child is undergoing treatment for cancer, parents may become consumed by the desire to protect their child from injury or infection. There is an understandable reason for feeling this way; when a child's blood counts are low, there is a much greater risk of bleeding or serious infections.

When treatment ends, parents who are overprotective may find it difficult to relax their vigilance, even after the treatment team gives its blessing for the child to be more physically active. Possibly this overprotection reflects the parents' feelings about the child's illness as well as a desire to ward off injury or infection. You almost lost your child and you want to believe that it is in your power to prevent that from ever happening again. Being overprotective seems like a way to regain control over a situation that made you feel vulnerable and defenseless. In reality, however, this approach may impede your child's ability to readjust to life after treatment.

Although several months had passed since the doctor had given 7-year-old Roy a clean bill of health, his mother, Sharon, still agonized about easing the restrictions on activities that had been "off-limits" when he was sick. With Halloween fast approaching, Sharon had a decision to make. She knew Roy had his heart set on going trick-or-treating this year, since he had missed out on going the year before. But when the weather report predicted a cold snap, Sharon decided not to take any chances. On Halloween night, she kept Roy home. As a steady stream of trick-or-treaters paraded down his street, Roy stared glumly out the living room window. When his friends came to the door, Sharon thought she had never seen Roy so sad. As Roy's friends ran off toward the next house, Sharon vowed that next year, Roy would be out there with them, laughing and joking, no matter how cold it was on Halloween night.

Continued overprotection can be especially detrimental for adolescents struggling to assert their independence. By over-restricting the young person's activities (including, in some cases, school attendance), well-meaning parents can unwittingly delay or disrupt a child's timely return to normal life. It is crucial for parents to trust the physician's judgment regarding the safety and appropriateness of resuming sports and other physical activity.

If you are uncertain about whether you are being overprotective, ask someone who knows you well to evaluate your approach to setting boundaries for your child. If this "reality check" suggests that you are too protective, you will have to make a conscious effort to adopt a more relaxed attitude and find some other ways to manage your anxiety about the future.



Developmental Issues

The end of treatment poses challenges for children as well as adults. Children may feel just as anxious as their parents about ending treatment. Depending on their age and temperament, it may be hard for them to express their worries. At every stage of development, there is much you can do to promote healthy adjustment and help your child cope with the challenge of surviving cancer.

Infants, Toddlers and Preschoolers. Children who undergo treatment for cancer during the first five years of life have little understanding of what is happening to them medically. For infants, the key issue is the development of a trusting and responsive relationship with a consistent caregiver. Any inconsistency in the caregiving or separation from the caregiver can evoke fear or mistrust in the infant. Medical treatment that restricts the infant's ability to explore the world may trigger developmental delays. When treatment ends, the infant can make up for lost time in the acquisition of skills and self-awareness. You can stimulate healthy development by encouraging your child to explore "safe" territory when he or she wants to and allowing your child to cuddle and cling to you in unfamiliar surroundings, such as follow-up clinic visits.

For toddlers, the focus shifts toward asserting autonomy and control. If treatment disrupts the toddler's ability to master newly acquired skills or exert control over the environment, your child may regress. If you routinely gave in to your child's

stubbornness or temper tantrums during active treatment, it is essential to start setting limits again when treatment ends. If your toddler rebels or resists treatment during follow-up visits, it is important to enlist the support of the staff or other family members in setting and enforcing limits. If you anticipate a problem, don't hesitate to call ahead and line up help in advance. Or ask your spouse to accompany you on follow-up visits so that you can set limits together. At times like these, you need all the help you can get. It is never easy to manage your child's behavior in public, when you feel sensitive to how others may be observing and judging the way you relate to your child. It is doubly difficult to provide consistent discipline when your child needs a mega-dose of comforting and cajoling to get through painful procedures.

Between the ages of three and five, children are old enough to have memories of their treatment. As a result, they may become extremely anxious at the prospect of painful procedures. This may lead to uncooperative or regressive behavior during treatment. If discipline becomes lax, move quickly to restore order and consistency when treatment ends. If your preschooler has lots of questions about treatment, try to answer them as honestly as you can, in a way your child can understand. If unresolved fears or concerns surface, prompt your child to express his feelings through art or play.

Early School Years. The most formidable issue for the 6- to 9-year-old cancer survivor is negotiating the return to school. The school environment plays a major role in developing academic and social skills. The seriously ill child who has been challenged by frequent absences, isolation from peers and the physical effects of cancer treatment may have difficulty readjusting to school after treatment ends. The strategies discussed in the *School* section of this booklet may be helpful in easing the adjustment and enabling your child to overcome threats to self-esteem, peer acceptance and academic achievement.

Once you get the physician's okay, encourage resumption of activities that are appropriate for your child's age and stage of recovery. Fight the impulse toward being overprotective. Keep in mind that participation in these activities helps to rebuild your child's self-confidence and friendships. However, if the prospect of group activities or team sports makes your child anxious, don't push it. Arrange one-on-one playdates or nurture a single friendship to help your child readjust to peer-interaction in a less threatening way. These intimate social encounters may also provide an ideal setting for rehearsing responses to the questions or comments the child will face from classmates and other acquaintances.

When treatment ends, children at this age may be preoccupied with thoughts about the illness or haunted by fears of recurrence. It is important to give your child the opportunity to express and work through these feelings. Let your child know that it is okay to be worried or afraid. If your child wants to know what will happen in the future, be honest. If you don't have an answer, say so. Though you cannot guarantee the cancer will never return, help your child focus on the positive aspects of completing treatment. And reassure your child that no matter what happens, you will take care of him or her.

Pre-Adolescence and Adolescence. The restriction of freedom caused by prolonged illness and treatment is acutely distressing to the 10- to 18-year-old. Isolation from peers and the debilitating effects of treatment foster an overdependence on caregivers at an age when children need and want greater independence. As a result, the adolescent with cancer may become frustrated, angry, withdrawn, depressed or rebellious. These reactions are entirely valid and reasonable.

The end of treatment may provoke increased anger and rebelliousness, especially in adolescents who are eager for things to “get back to normal.” Those who feel emotionally ready to resume activities may clash with parents who are overprotective. To promote healthy development, encourage resumption of activities as soon as medical approval is given.

The same advice applies to children who are overdependent and are reluctant to resume activities. These children may be fearful about giving up their close-knit bond with a primary caregiver. If this is your situation, try a more gradual reintroduction of activity. As your adolescent begins to reassert independence, his or her self-reliance will increase.

As your child matures, it is important to keep the lines of communication open. Encourage expression of fears and worries, but respect privacy if he or she does not feel like talking. And take all concerns seriously.

Meeting Sibling Needs

Recognizing and responding to the needs of healthy siblings is a critical component of adapting to life after treatment ends. Like adults, siblings often struggle with ambivalent feelings. They may understand that the ill child deserves the lion's share of your attention, but they still feel resentful or disappointed. Even though they may know how much you care about them, they cannot help feeling like they are less important.

It is difficult for siblings to express these thoughts because they feel guilty about having them. After all, they are not the ones who had to suffer through painful procedures or devastating physical changes. Many siblings feel like they don't have a right to complain because their problems seem inconsequential compared to what the ill child has been through. To complicate matters, they may continue to worry about the health of the sibling with cancer long after treatment ends.

Validate your healthy children's feelings. Let them know that you understand how difficult it's been for them to live through their brother's or sister's illness and treatment. Urge them to express their emotions. If it is too hard to talk about their feelings, encourage siblings to express themselves through art, creative writing or play. Older siblings may prefer to vent their feelings in a diary or journal or through an online teen support group.

Above all, make an effort to let siblings know they are special, too. Praise their achievements and find small ways to show your love and appreciation. Even though your ill child may continue to require more of your attention, make time to cuddle, read a story, cook a favorite food, or plan an outing with a sibling. It may not seem to you that you are doing much, but it will go a long way toward helping your healthy children adapt to the family's changing circumstances.

Putting the Illness in its Place

Arguably the biggest challenge you may face in the post-treatment period is restoring a sense of balance in your family's priorities. While your life may never return to the way it was before cancer invaded your world, your family must find a way to adapt to changing needs. While you will always walk the tightrope between hope and uncertainty, you must create your own emotional safety net. And while there are no hard and fast rules to follow, you must establish a survivorship protocol that works for you.

One way to ease the transition to life after treatment is to focus on the metaphor of "putting the illness in its place." This approach, as developed by Jamie Ostroff and Peter Steinglass at Memorial Sloan-Kettering Cancer Center in New York, helps families identify the ways in which childhood cancer has had an impact – either positive or negative – on their lives. While this approach may be valuable for anyone coming off treatment, it may be particularly valuable for families that have a hard time letting go of illness-focused needs and priorities.

The approach may also be helpful for families at the other end of the adjustment spectrum. These families are so intent on “getting back to normal” that they make a concerted effort to avoid talking about the illness. Under the guise of protecting each other from further pain or anxiety, family members may enter into a “conspiracy of silence” by suppressing any discussion of cancer-related concerns. Unfortunately, this strategy can backfire. Discouraging family members from expressing their feelings can contribute to isolation and an even greater preoccupation with cancer memories and concerns. By putting the illness in its place, these families are able to achieve their goal in a way that allows all family members to acknowledge and work through their emotional reactions to the illness.

Honoring the Illness. The first step in putting the illness in its place is to acknowledge it exists. “Honoring the illness” means giving yourself permission to acknowledge all the emotions you are experiencing. You will almost certainly experience a sense of exhilaration for having survived a life-threatening illness. Some of your other reactions, however, may surprise you. Even though the “crisis” has passed, you may feel more anxious and worried than you did before. You may be overwhelmed by feelings of loss even though your child has survived. The truth is you have suffered a loss. Your life has changed. Once you take the time to reflect on all you have been through, you may discover ways in which it has changed for the better. Despite the tension and the strain, your family may have become closer. You appreciate your children more and marvel at their resilience and compassion. You have learned who to rely on when it really counts. And you recognize your own strengths and realize that you have a valuable perspective to share with other families.

If you find it difficult to acknowledge your feelings, or to deal with the extremes of emotion you are experiencing, you may find it helpful to join a post-treatment support group. The opportunity to compare your experiences with those of other families can help clarify your own family’s attitudes towards the illness. Clarifying your own issues can also help you identify future goals and explore strategies for achieving them.

Reestablishing Family Life. Dealing with your child’s illness used much of your family’s time and, most likely, a disproportionate share of your physical and emotional energy as well. In order to put the illness in its place, you must become more aware of its presence in your home and in your family’s routine. That is a key step in being able to assess how much you want to let the illness remain in your life.

I will be a Vet
when I grow up.



Begin by asking yourself, “How has the illness immersed itself in my home?” Then, look around your house and identify specific things that remind you of the illness. These may include medical supplies, medicines, wigs, caps or scarves, get well cards, hospital wristbands, even the stuffed animals that accompanied your child to the hospital. Examine these reminders. If any make you uncomfortable, you may want to dispose of them. For example, gather up the medical paraphernalia you no longer use and discard it. Or consider donating it to an organization that recycles such supplies to needy families. Be sure to take everyone’s feelings into consideration to avoid parting with items prematurely. Conversely, if there are comforting reminders that have been hidden away, you may want to relocate them to a more visible spot in your home.

Next, evaluate how the illness has come to dominate or take the place of family activities. In particular, think about the kinds of activities, hobbies, rituals, or recreational pursuits you have had to curtail or eliminate in order to meet your child’s more acute needs. Then consider reinstating some of the activities you most enjoyed doing prior to the illness. These might be personal pleasures, such as taking an exercise class or meeting a friend for coffee once a week. Or they might be family outings, such as going to a ballgame or having a picnic in the park. Making a conscious effort to reintegrate these normal routines and activities into everyday life helps families effect the transition to survivorship more successfully. Conversely, if there are pleasurable rituals that began during the illness, such as reading to your child or playing board games together, you may want to make an effort to continue these activities.

Breaking the Conspiracy of Silence. One of the most important ways to put the illness in its place is to create a climate of open and honest communication. Give family members room to express their fears, feelings and frustrations. Accept the fact that everyone in your family may have different needs when it comes to talking about the illness. Respect those who don't want to talk about it and let them know you'll be there to support them whenever they're ready. Learn what works with each of your children and adjust your approach accordingly.

If you and your spouse see things differently, try to understand your partner's point of view. Remember that there is more than one valid way of coping with change. The important thing is to keep talking.

At a support group for families adjusting to life after treatment, Bonnie and Arnie talked about some of the ways they had begun to reestablish their family life after their daughter Tina's bone marrow transplant. When 15-year-old Tina first came home, she continued to maintain social contact via phone and email as she had during her months of isolation. But even after her doctors gave the okay for Tina to have visitors and resume activities, she was reluctant to leave the house or have anyone see what she looked like. Tina's parents realized they would have to proceed slowly in helping Tina reconnect with the outside world. They started off with a few modest excursions to the video store, a favorite restaurant, a nearby park. They encouraged Tina to resume her violin lessons and to invite a couple of close friends for a sleep-over. Gradually, Tina became more comfortable being around other people. She started going out more. In September, she was ready to go back to school. But the real turning point came a couple of months later when Tina asked her parents for permission to attend a weekend youth group retreat. Though they worried it would be too exhausting, they agreed to let her go. All weekend, they wondered if they had done the right thing. But the moment she stepped off the bus, looking positively euphoric, they knew it had been just what she needed to bolster her self-confidence and renew her enthusiasm for living.

As John, another member of the support group, listened intently to Bonnie and Arnie's family's experiences, he realized that Bonnie and Arnie's patient, yet deliberate efforts to promote socialization might be exactly the kind of approach that would work with his son, Jamie, age 12. When John glanced at his wife, he could tell she was thinking the same way. They smiled at each other, knowing that the insights they had gained from the support group had given them a whole new perspective on how to deal with their own family's situation.

Summary. When active treatment ends, families that have adapted to the demands of childhood cancer face the challenge of shifting the balance between “illness” and “non-illness” priorities. Putting the illness in its place is a multi-step process. Some families may be able to implement this approach on their own. Others may need help with the transition.

Give yourself time to put the illness in its place. You have weathered a major storm and it will take time to reshape your world. Even after you adjust to this new phase of your life, the memory of what you have been through may come flooding back unexpectedly. The anniversary of your child’s diagnosis or a conversation with the parent of another child with leukemia or lymphoma may trigger a potent emotional reaction. If these memories become so intrusive that you feel you cannot handle them, seek professional counseling. There are therapies available to help make the memory of the illness more manageable. More often than not, however, these memories will be sharp but fleeting reminders of past experiences. If you are able to honor the reaction and allow yourself to think about it, you should be able to get through it and move on.

Finally, remind yourself that there is, indeed, life after cancer. With your child’s health restored, you can look forward to a future filled with hope and promise. And by putting the illness in its place, you will emerge from this extraordinarily stressful experience with an enormous repertoire of skills that will enable you to cope effectively with any future crises that may occur.

Addressing Concerns about the Possibility of Death

The emphasis throughout this booklet has been on life and living. Medical advances have most certainly increased the chances for children diagnosed with leukemia or lymphoma to live long and happy lives.

However, these are life-threatening illnesses. Most families, including the children, have questions about the possibility of death even while they are very focused on living. While they are optimistic about conquering the disease, concerns still arise about dying. For most, the concern recedes as treatment progresses to a successful conclusion. But despite the fact that medical advances have significantly increased survival rates, treatment efforts are not always successful. In this section we will discuss how parents and children can openly discuss questions and concerns about possible death.

One of the primary concerns in families living with a life-threatening illness is communicating about the possibility of death. Who gets told that a child has a life-threatening illness? When do you tell children about the possibility of death? How do you discuss the possibility of death with children? In our experience, we have found that honesty with brothers and sisters, as well as with the child with leukemia or lymphoma, is the best approach. This applies throughout the course of treatment and in the event it becomes necessary for a family to prepare for a child's death. Most treatment teams have members who are trained to help parents prepare for these discussions; ministers, priests or rabbis can also help.

We have emphasized repeatedly that in discussions with children, honesty is the best policy. But when it comes to the subject of death, there are some special considerations. In an age when we have virtually unrestricted access to information, we have come to believe that the more information you have, the better. But information is not synonymous with honesty. There is a danger in overloading children with information about death and dying. Knowledge can be empowering, but it can also be frightening and overwhelming.

Being honest with your children does not mean providing all the information you have available to you. It means being honest about your feelings. It means being honest with yourself about how much information you think your child can handle. And it means being able to screen information and present it in a way that is appropriate for your child.

When communicating with your child about difficult subjects, the best advice is to listen carefully to your child, acknowledge his worries and fears, and respond accordingly. Be alert for nonverbal cues or behaviors that may reflect feelings your child is unable to express directly. These indirect forms of communication can be quite revealing. If you sense that your child is feeling confused, isolated or lonely, you may need to provide more information or reassurance.

Any discussion about death must be tailored both to the developmental level of the child and to be in accord with a family's spiritual and/or religious beliefs. A child or adolescent's personal experience of death (with the loss of a family member or peer) is another consideration. Concepts of death are age-related in children, with wide individual variations. Attitudes and concepts do not change abruptly at a given age, but evolve gradually.

Infants, Toddlers and Preschoolers. During the first two years of life there is no understanding of death. Fear of separation from protecting, comforting persons is present in its most terrifying intensity. While death is not yet a fact for the child going on three, anxiety about separation remains all-pervasive.

Between the ages of 3 and 5, most children begin to comprehend death as something that happens to others. At this time, the concept of death is still vague. It is associated with sleep and the absence of light or movement. It is not yet thought of as permanent. In contrast to toddlers, most children of this age are able to withstand and understand short separations. They often respond more spontaneously and with less anxiety to questions about death than do older children. They are also curious about dead animals and flowers. It is at this age that children are especially involved with magic. Preschoolers feel that wishes can become real. The child may wish that mom, dad, brother or sister would go away and never return; therefore, there may be anguish and guilt when a parent or sibling dies.

Children between ages 3 and 5 deny death as a final reality. They believe death is accidental and they themselves will not die. They believe that it is reversible.

Early School Years. From approximately the age of 6 years and onward, the child gradually accommodates to the proposition that death is final, inevitable, universal and personal. Many 6- and 7-year-olds suspect that their parents will die someday and that they, too, may die, but only in the very distant future.

Children between ages 5 and 9 years show a strong tendency to interpret death as a person who will take them away from their family. Many children are horrified, confused and angered at their first discovery of death. In brief, the child under 10 is beginning to come to grips with the concept of death, but has not yet attained a well-developed understanding of death.

Children under 10 generally do not ask direct questions about death. They wait for adults to show readiness to anticipate and deal with their concerns. The absence of expression of anxiety about death does not mean there is lack of concern. While some 5-year-olds may talk freely about death, most children find it difficult to express their feelings openly, and thus are often thought to lack anxiety about the subject. Many of their feelings may be underground; thus, reports that a particular child has absolutely no fear may really only be a report of that child's lack of expression.

Pre-Adolescence and Adolescence. Piaget, a famous child psychologist and philosopher, suggests that as a child approaches adolescence, at about age 11 or 12, he is equipped with the intellectual tools necessary to understand both life and death in a logical manner. At about the age of 10, the fact of the universality and permanence of death finally becomes understandable.

The child of age 10 accepts death as a natural phenomenon and the fact that all people must die and that he himself must die. He thinks that his own death is still something that will probably not occur for a very long time. Death is something that happens to “old people.” Older adolescents, of course, have an understanding more like adults that death can come to anyone at any age. Since they think their lives are just beginning, they find it difficult to believe that they might die anytime soon.



LEUKEMIA

LYMPHOMA

MYELOMA

In summary, the child under 5 years old lacks almost all of the mental operations required to form the concept of death, even in a beginning manner, except for his understanding of the concept of separation. By the age of 11 or 12, the concept of death is fairly well-established. In the middle years, ages 6 to about 10, the child has some appreciation of the fact of death, but has not yet come to full adult awareness of the concept. Adolescents are more mature in their thinking.

Helping Children Understand Death. The following points are important for parents to consider discussing with their children, including both their child with leukemia or lymphoma as well as brothers and sisters. It is recommended that these discussions occur sometime during the early phase of treatment. Some children may benefit from parents regularly asking them if they have questions or concerns about what is happening or what could happen. For children who are less likely to ask questions directly, it may be necessary for parents to present important information and encourage discussion and their questions. Use language that fits with your child's age and raise points in a tactful manner. Family discussions that include all children in the family are often helpful and may encourage family members to help each other through stressful times. At other times, a child may benefit more from one-on-one discussion with a parent. Here are some helpful discussion points.

(1) Death, like birth, is a part of the natural order of things. It is normal for living things to die. Flowers, plants, trees, animals and people all die sometime. It happens sooner for some people and later for others. Talking about death does not make it happen. Talking about death does not mean that we think it is going to happen anytime soon. "Leukemia" or "lymphoma" is a very serious illness. People who get leukemia or lymphoma are given special medicines which almost always help them get better and live for a long time. Sometimes when the special medicines don't help a person get better, the disease can cause a person to die.

(2) Death has social significance. We have special feelings for special people we share our lives with (our families and friends), and they have special feelings for us too. People never forget special people in their lives, even when they die. When someone dies, the special feelings stay with each person.

(3) The loss is never complete: The person who dies lives on in some way. Here, the specific cosmological and/or religious beliefs of the family are critical; some feel that the child will live on in spirit, others that the child will have passed on a legacy of the meaning of life to friends, and others that the child will live on in both body and soul for eternity.

(4) Children need to be reassured that it is all right to cry and feel sad. A child with leukemia or lymphoma often feels sad when thinking about his or her illness. Brothers and sisters, and moms and dads feel sad and cry, too. It is all right to feel angry and resentful. Children need to be reassured that it is all right not to want to discuss their illness or possible death. Sometimes it is best for a child to tell others bluntly that he or she does not want to talk about it right now. Then, when the child is ready to talk about his or her illness or possible death, the adults in his or her life need to be ready to listen and provide support.

(5) Children also need to be reassured that silence is acceptable. It is not necessary to express all feelings in words. Sometimes it is easier for children to displace their feelings through play and use of toys to express their feelings. In other words, it may be easier for them to talk about what teddy bear is worried about.

(6) Adolescents may prefer to talk with an uncle or aunt or close family friend or member of the treatment team about their fears about dying. As noted before, this may be because they wish to spare their parents pain.

If Death Must Come

While the number of children who die from leukemia and lymphoma continues to decrease with medical advances, some children do die. Parents whose children have died say they were aware of the point when living with the illness changed to preparing for death. You may want to consider the following discussion points if you need to prepare a child for his or her death, or prepare a child for the death of a brother or sister.

These points are highly subjective and are listed here because they have proven helpful in conversations with children. It is recommended that they be used with caution and judgment, considering the child's age, developmental level and readiness. Parents need to be prepared to talk with children of any age about what they believe from a spiritual or religious perspective happens after death.

The content of communication with children is important; yet all sorts of things can be said and all sorts of "mistakes" can be made. Children often pay less attention to what is said, and more attention to the manner and concern with which it is said. Children tend to overlook "mistakes" in communicating. What matters to them is that the way they are spoken to matches their ability to understand and participate in the

conversation. No matter how well-rehearsed and “correct” the content is, if you are not in tune with the child, the conversation often will become one-sided.

It is important to assess the readiness of the child. What is said early in the illness will be more in a context of hope for a lengthy survival. In the event it becomes necessary to shift the focus of care to preparing for a child’s death, what is said is best presented in the context of providing comfort and support. Children tend to ask questions when they are ready to hear the answers. All of a child’s questions need to be answered honestly and tactfully. Understanding should be provided to the degree it is requested by the child and contributes to her comfort and support.

(1) It is important to reassure children that they will not be alone in death and that the parents will remain with them even after death. All children need to know that parental presence and support are maintained even in death. This point is essential to children and needs to be phrased within the context of the parent’s spiritual or religious beliefs.

(2) At the time of death, a person needs to know that he or she has done all he could do with his life. This is a universal human concern. Even children who die at an early age can have meaningful, happy lives and make lasting contributions to human relationships. Young children can touch the minds and hearts of those they deal with at school, in the hospital and at home. It is beneficial to point out that, to the dying child, (or to his or her siblings) the child’s life and death can touch another person, he or she will have left a mark and will have led an effective life.

(3) When death finally comes, it will not hurt. There may be pain in the period leading up to death, but doctors will do what is necessary to reduce the pain to a minimum. Death itself will not hurt. After death the pain will never return. Children are very concerned with having the pain finally end. It is important to reassure them that it will.

(4) When a loved one dies, it is important for us to be able to say goodbye. It is okay for families to cry and grieve together with their loved one who is dying. Sometimes the person who is going to die may want to say goodbye to friends. There are many ways for people to say goodbye: in person, by telephone, by writing letters or having another person deliver a message on their behalf. After someone dies, people have a custom of saying their last goodbyes together. In Western cultures, these goodbyes are called funerals. People should not be afraid of funerals. They are very important and make the family feel better. Adults do this in the privacy of their homes or in

church. After the funeral, the child's mother and father may want to have their child's friends over to talk about their child and how much they loved her.

(5) Adults sometimes do not know very much about death either. If parents talk with a doctor and cry afterwards, or if they talk about their child's illness and become teary-eyed, it is because they love the one who is going to die and will miss this person. However, if a child has to die, parents, family and friends still have the opportunity to remember the happy times, and memories about the child will live on. Talking to your own child about his or her own possible early death or the death of a brother or sister is very difficult. It is accompanied by enormous pain and great concern with a heavy price on your own emotions and feelings. The reward for your efforts will be a child who realizes that he or she is not alone in facing the most difficult task all of us ultimately must face: the fact of our own death. The failure to make the effort can only lead to isolation, loneliness and hurt. Making the effort has as its reward the fullest gifts that can be shared by anyone of us with our children: love, understanding and the continuation of life.

Physical Preparation. Taking care of necessary physical and legal matters is one of the most difficult tasks because it is a visible sign of imminent death. It is recommended to prepare ahead of time, days or even weeks before the death. While difficult and painful, early preparation allows the family members to do so more calmly and with presence of mind.

Talking about it and doing it are both very important. If preparations are done early and calmly for such necessary matters as funeral and burial, much of the later grief and frustration can be alleviated. Many parents who handled the death of their child or young adult exceptionally well told us that they had made plans for the funeral and burial weeks ahead of time. These plans included decisions regarding autopsy, method of burial and, as important to the dying child, methods of disposing of treasured possessions.

Children often want to know who will take care of their little dolls or trucks or favorite things. Some parents encourage their children to help decide what toy will be given to a certain friend or brother or sister. Other details of funeral and burial are best discussed privately, separate from the child who is dying.

Above all, early preparation assures that when death does occur, the family members will not be burdened with additional concerns, but will be free to support one another emotionally.

Dying in the Home. Parents and the medical team may wish to consider caring for a sick or dying child at home rather than in the hospital. This has become practical in recent years with the easy availability of many hospital techniques for use at home, such as oxygen set-ups, IV systems and the growing willingness of the hospital medical teams to provide the necessary physical and emotional support. The decision for a child to die at home is usually considered when the focus of care has changed from trying to arrest the disease to making the child comfortable.

It is encouraged that both the patient and the family agree on this plan of care with the availability of the medical team to provide backup to the family and the patient. Many patient families report that this arrangement is technically easy to set up and, most important, that it makes possible a close and caring environment.

Putting the Family's Life Back in Order

Parents whose child has died have told us about things that helped them get their lives back in order. Without exception, they say the emotional pain is intense, no matter how long and hard one prepares for the death. They have also told us that time helps. After several months, while the loss is still felt very deeply, the emotional pain is much less intense.

Prayer reportedly helps a great deal. Talking to a spouse and to close friends helps. Talking to your other children places the events in perspective and enables them to develop an understanding for the meaning of that life and death.

Keeping busy is essential. Without exception, the more than 100 parents we talked with said that going into despondency is not good, and that keeping busy, in whatever way best suits the individual, helps time to do its healing. Some parents, for example, have gone back to work or taken jobs for the first time. Some have become involved in disease-related projects, such as fundraising for research. Others help to establish support groups for parents who have undergone a similar loss. Still others take the family on extended vacations or long trips, especially during the first year, to help them place the life and death in perspective.

Parents have told us that their memory of the sorrow fades and the memory of life with the child remains. As they get farther from the death, their memories of happy events with the child become stronger. They never forget, and the memories become their happiness and give their child's life meaning. Years later, parents recall that they still derive strength from memories of their child's strength in illness and death itself.

No matter what other problems arise — financial, physical or emotional — these things no longer overwhelm them.

Their child left them a legacy of strength, of determination to fight problems and not to run from them, of concern for others. What their child left them, above all, was a realization of how short life is and how much we should enjoy and savor every minute.

This is a great deal for a child or young adult to have taught her own parents. But the children have done so, and they will continue to teach us, by their way of facing life and death, that we can all grow stronger and closer if we face our problems together.

Putting the Family Life Back in Order for Brothers and Sisters. The death of a brother or sister is a very traumatic experience at any age. Family life changes when a family member is diagnosed with a life-threatening disease, with treatment and with the end of active treatment. It changes again with the death of that family member. While feeling their own confusion, sadness, fear, anger and grief, children are also aware of their parents being different. Children experience omnipotence and feel responsible for their parents' feelings. Often children feel a sense of responsibility for the death. They experience angry and resentful feelings during the course of living with a brother's or sister's life-threatening illness because of the impact it had on their own life and relationship with their parents. Sometimes, children feel survivor guilt that they were able to live when a brother or sister was not.

The time following the death brings with it new issues to confront. It is important for families to spend time talking about how a child's life-threatening illness and his death made each surviving child feel and how it changed life for them. Families that openly grieve, cry, question and communicate their personal experiences with one another are more likely to identify the perceptions and misperceptions as well as ease the painful, confused and sad feelings of surviving brothers and sisters.

Children do not grieve or deal with feelings in the same way adults do. Many parents find it difficult to understand how children can play and continue on with their lives in ways that are not possible for adults. Adults use cognitive and verbal skills that children have not yet developed to help identify and deal with their feelings. Children use play to help identify and deal with their feelings. Active children may deal with their feelings in ways that allow them to vent feelings through physical activity. Others may draw or use art to express their feelings when words are not available to them.

When parents are able, it can be healing to both parents and surviving brothers and sisters to spend time involved in activities together.

As surviving brothers and sisters grow older and develop an increasing ability to understand the changes that occurred with the family, it is important to revisit memories of the brother or sister who died. With time these discussions are less painful. New exchanges help growing children understand life and death and their family's experience with a new level of understanding and in ways they were unable to perceive at a younger age.

For surviving brothers and sisters, life does go on. While living through the difficult times of losing a family member to leukemia or lymphoma, it is possible for brothers and sisters to grow and learn about life and death from this painful experience. With time, it is important for parents and family members to help a surviving child focus on his or her own life, feel good about himself or herself and live life to the fullest.

The Leukemia & Lymphoma Society would like to acknowledge Karolyn Smith Wolverson, Ph.D., who contributed much of the material in the sections "When Treatment Ends" and "Putting the Illness in its Place."

Resources for Adults

Chesler MA, et al. "Voices from the margin of the family: siblings of children with cancer." *Journal of Psychosocial Oncology*. 1991;9(4):19-42. An updated version of this article was written by the same author. "Guidelines for assistance to siblings of children with cancer." *Medical Pediatric Oncology*. 1999;33:395-398. http://www.icccpo.org/articles/psychosocial/guidelines_siblings.html.

Chesler MA, et al. *Cancer & Self-Help: Bridging the Troubled Waters of Childhood Illness*. Madison: University of Wisconsin Press. 1995.

Deasy-Spinetta P, Irvin L. *Educating the Child with Cancer*. Bethesda: The Candlelighters Childhood Cancer Foundation. 1993.

Johnson LF and O'Donnell E. *The Candlelighters Guide to Bone Marrow Transplants in Children*. The Candlelighters Childhood Cancer Foundation.

Keene N. *Childhood Leukemia: A Guide for Families, Friends & Caregivers*. 2 ed. Cambridge: O'Reilly and Associates, Inc. 1999.

Keene N, et al. *Childhood Cancer Survivors: A Practical Guide to Your Future*. Cambridge: O'Reilly and Associates, Inc. 2000.

Laszlo J, M.D. *The Cure of Childhood Leukemia: Into the Age of Miracles*. New Brunswick: Rutgers University Press. 1995.

Lauria MM, et al. *Psychosocial Protocol for Childhood Cancer: A Conceptual Model*. *Cancer*. 1996;78(6):1345-1356.

Lozowski Sullivan S, Ph.D. *Know Before You Go: The Childhood Cancer Journey*. Bethesda: The Candlelighters Childhood Cancer Foundation.

The Leukemia & Lymphoma Society. *Long Term and Late Effects of Treatment for Blood Cancers*. Fact Sheet. 2004.

Resources for Children & Teens

Bombeck E. *I Want to Grow Hair, I Want to Grow Up, I Want to Go to Boise*. New York: Harper & Row. 1989.

Buscaglia L. *The Fall of Freddie the Leaf*. Thorofare, NJ: Slack, Inc. 1982.

Canfield J, et al. *Chicken Soup for the Surviving Teen-Age Soul*. Deerfield Beach: Health Communications, Inc. 1997.

Landier W, Scott T. *My Central Line Book (Mi libro de mi linea central)*. Bard Access Systems.

Lilleby KU. *Stevie's New Blood*. Oncology Nursing Press, Inc. 2000.

The Leukemia & Lymphoma Society. *The Stem Cell Transplant Coloring Book*. 2005.

Webisodes: Coping with Chemo. A series of short, animated, Web-based movies for teens about diagnosis, side effects of chemotherapy and feelings about coping with illness. Produced by the Starlight Starbright Children's Foundation and supported by The Leukemia & Lymphoma Society. To view go to www.slsb.org/chemo/.

National Organizations

American Camp Association
5000 State Road 67 North
Martinsville, IN 46151-7902
(800) 428-CAMP or (765) 342-8456
www.acacamps.org

Brave Kids
www.bravekids.org

The Candlelighters Childhood
Cancer Foundation
National Office
PO Box 498
Kensington, MD 20895
(800) 366-2223 or (301) 962-3520
www.candlelighters.org

National Cancer Institute
International Cancer Information Center
NCI Public Inquiries Office
Suite 30368
6116 Executive Blvd. MSC8322
Bethesda, MD 20892
(800) 4-CANCER
www.nci.nih.gov

CureSearch
The National Childhood Cancer
Foundation and The Children's
Oncology Group
www.nccf.org

National Children's Cancer Society
1015 Locust, Suite 600
St. Louis, MO 63101
(800) 315-2580 or (310) 479-1212
www.children-cancer.com

National Information Center for
Children & Youth with Disabilities
PO Box 1492
Washington, D.C. 20013
(800) 695-0285
www.nichcy.org

Outlook: Life
Beyond Childhood Cancer
www.outlook-life.org

The Starlight Starbright
Children's Foundation
1850 Sawtelle Blvd., Suite 450
Los Angeles, CA 90025
(310) 479-1212
www.slsb.org