Sibling Resources

SIBLING program
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When Your Brother or Sister Has Cancer

Adapted from a booklet prepared by Laura A. Rudolph for the Children’s Orthopedic Hospital and Medical Center, Seattle, Washington.
This book is for you because you’re important.

Being the brother or sister of someone with cancer can really be hard. Cancer is a serious disease, and it can be hard to understand. Plus, there are a lot of things doctors still don’t know about cancer. So it’s hard to know what will happen.

It’s normal for you and your family to be worried or upset. Here, we talk about some of the thoughts and feelings you may have. Some may seem bad, but they’re all OK to feel and OK to talk about!

If you have questions or worries about your brother or sister, please talk to a grown-up. It might be your parents, or a grandparent, aunt, uncle, or another grown-up you are close to. They can help you, or maybe find someone at the hospital who can. The doctors and nurses will be glad to answer any questions you may have.

Finding someone you can talk to is a good way to start feeling better.

At first it’s hard for everybody. But once your brother or sister is in remission – which means the cancer is under control – everyone will feel much better.
The first few weeks

When kids have cancer, it can be hard for everybody in the family. Many times the sick child will have to stay in a hospital for a while to get special tests and treatment.

Usually when kids are in the hospital, one parent stays with them or spends a lot of time with them. Their other parent may also stay in the hospital or spend a lot of time going back and forth. Brothers and sisters may need to stay with friends or family during this time. You may feel left out and not really know what’s going on. And it can be hard to not see your parents as much as you’re used to.

Things are usually less busy after the first few weeks. Children with cancer tend to leave the hospital and then get their treatments by going to a clinic or doctor’s office. Sometimes they need to go into the hospital for treatments, but in many cases this is only for a short time.

We hope those times that your brother or sister feels sick will be short. Soon they may be up doing everything they used to do.
**Worrying about your brother or sister**

You may really worry about your sick brother or sister. You may even worry about whether your brother or sister will die. Cancer treatment is tough to go through. It has to be strong to stop the cancer cells, but it’s hard on the good cells, too. It hurts to see someone you love lose hair, gain or lose weight, or not feel good.

You may feel strange about feeling good and being able to go out and do fun things while your brother or sister is stuck at home feeling bad. But it’s important for families to try to live as normally as possible. It’s important for everyone to try to keep doing the things they’ve always done.

**Feeling sad**

You may feel sad sometimes. You might see your brother or sister not feeling well enough to do things they usually like. They might feel bad and even cry. It’s a sad thing for someone you love to get sick and have to get tests done and take lots of medicine. But this time of sadness usually goes away when your brother or sister starts to feel better and things at home get back to the way they were before cancer. When everyone else feels better, you’ll feel better, too!

Doctors have good medicines and treatments for cancer, and most kids with cancer will get totally well. So, while you may feel sad or worried sometimes, it’s OK to think everything will work out.
Feeling guilty

Sometimes you might feel guilty. You may wonder if you did something or said something to make your brother or sister get cancer.

Remember that just because you think or even wish something, that doesn’t make it happen. People sometimes have bad thoughts about
others, especially when they’re mad at them! This is normal, and everyone does it every now and then. Cancer is a mystery. No one knows for sure why it happens to some kids and not to others. But one thing is for sure: You did not do anything to make your brother or sister get sick or get cancer.

Josh’s little sister, Patty, was diagnosed with rhabdomyosarcoma, a muscle tumor. The week before she was diagnosed, the two of them were playing. Patty grabbed Josh’s controller away from him. Josh got really mad, and yelled, “Patty, I wish you weren’t here! I wish something would happen and you’d have to go live somewhere else! Then you couldn’t take my stuff and mess up my game!” When Patty was diagnosed with cancer and had to go into the hospital, Josh felt awful. He blamed himself and thought that he caused the cancer because of what he said. He finally told his parents about what he had said, and they told him that he had nothing to do with Patty getting cancer, which was true. This made Josh feel much better.
 Feeling jealous and left out

Sometimes you may find yourself feeling jealous of your sick brother or sister. This is not surprising. Missing school, getting lots of attention, and spending extra time with mom and dad can look like a pretty good deal! And sick kids sometimes get presents and special treats, too. People want to do things to help them feel better.

Even though you know that your brother or sister needs this extra care and attention right now, it can be hard to accept.

Many times, brothers and sisters feel jealous, left out, and even think people don’t love them as much as the child with cancer. Feeling like this may then make you feel bad, too. It’s important to remember that it’s normal to feel this way. Also remember that you are loved just as much as your brother or sister. If you were sick, you would get lots of attention, too.

It’s OK to feel upset sometimes. It’s normal to feel jealous, and it’s OK to talk about these feelings. You don’t need to feel guilty about feeling this way, and you don’t need to keep these feelings inside you. Most kids with a sick brother or sister feel the same way.
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Ronnie’s little sister, Donna, had cancer. It seemed like she got all the attention. It was even harder for Ronnie because he had to stay with an aunt he didn’t really like while his sister was in the hospital. He felt left out, jealous, and thought his parents didn’t love him anymore. He didn’t want to talk to his parents about it because they already had a lot to worry about, and he felt bad for even thinking this way.

But, when Ronnie’s parents noticed how quiet and sad he was, they asked him to talk about how he felt. It made Ronnie feel much better to see that his mom and dad really did love him just as much as they always had. They were worried about him, too, and wanted him to talk to them any time he needed to.

Jocelyn’s brother, DaVon, has leukemia (a type of blood cancer). Jocelyn had a slumber party planned for Friday night, but DaVon got sick and had to go to the hospital. Jocelyn had to cancel her party and stay with her aunt and uncle all weekend. It wasn’t fair! She was really mad. She was mad at DaVon; she was mad at the leukemia; she was mad at the world!
Feeling angry

Your brother’s or sister’s cancer can, and will, upset everyone in your family. It can make people angry because no one knows what to expect. One minute everything is going well; then suddenly it’s not. You may also feel afraid. This is an important feeling to share because everyone in your family probably feels this way, too. If you let it out by talking about your anger or fear, it often seems to get better or even go away for a while.

When Jennifer’s sister, Mary, was first diagnosed with leukemia, her mother drove back and forth to the hospital every day to see her. One evening, Jennifer’s mother got really mad at her when she didn’t clean up her room like she was supposed to – much angrier than usual. This made Jennifer feel bad, and she wondered if her mom thought she was a bad daughter. But later her mother said she was sorry. She said she really wasn’t angry at Jennifer, but was worried about Mary and very tired. She apologized for taking it out on Jennifer. Later, Jennifer and her mother talked about how they were both worried and how they could help each other through this time.
Worrying about what goes on in the hospital or clinic

Hospitals and clinics can be pretty scary places. Your parents or your brother or sister may have told you about some of the painful tests or treatments that kids with cancer have to go through. Maybe they described some of the big machines in the hospital. Sometimes just hearing about things that are new and strange can scare you and make you worry about what really goes on in hospitals. You might imagine all sorts of things!

If this worries you, ask if you can go to the hospital to see for yourself. There may be someone who can show you around the hospital and answer your questions. Many hospitals also have take-home booklets or websites that show you the hospital and what treatment is like. Talk to your parents about what you’d like to know so you can better understand what’s happening to your brother or sister.

Brianna was very worried about her little brother, Tommy. She was worried he was going to get burned or be hurt when she found out he was getting radiation therapy. Brianna was really upset until her dad took her to the radiation department, and she talked to the doctors and nurses there. She was happy to learn that radiation treatments were quick and didn’t hurt at all!
Worrying that you or your parents might get cancer

Sometimes when you’re really upset about things, you can feel a little sick yourself. Your stomach may feel upset, or you might have trouble sleeping. Maybe you have bad dreams, or just don’t feel like doing anything. You may not want to go to school. You might want to be around your mom or dad more. You may be worried that you or other people that you love will get cancer, too. It’s normal to feel these things. As you adjust to the changes that are going on, these things should get better.

It helps to know that cancer is not like a cold. You can’t catch it from other people or from animals. It’s something that just happens, and no one really knows why. Cancer is not something that can be spread so that everybody in a family can get it. And it almost never happens that two kids in the same family get cancer. You don’t need to worry that you or your parents will get cancer. But if you feel sick or worried, talk to your parents about it so you can get help to feel better.

Missing your parents

You’ll probably miss your parents if they have to be away a lot during hospital stays or clinic visits. Sometimes it helps to talk to your mom or dad on the phone, or text, write notes, or email back and forth. You might ask to stay with a favorite person, someone you really want to be with, who can help you feel less lonely. Another thing you might do sometimes is go to the hospital to visit, if it’s OK with the hospital.

When your brother or sister isn’t in the hospital or going to the clinic a lot, maybe you can ask for a little extra time with your mom and dad.
Having a child with cancer is hard on parents. Because parents love all their children very much, it makes them sad if any of their kids are sick, have to go through things that hurt, or have to stay in the hospital. It’s really hard on parents if they’re worrying about lots of other things too, like work, taking care of the house, or having enough money to pay the bills.

Parents also worry about being there when each of their children needs or wants them. Your mom wants to be with you at home and at the hospital or clinic with your brother or sister. Your dad has to make the same tough choice about where to be. They have to keep going to work, too. There’s no good way to fix this problem. You know people can only be in one place at a time!

Sometimes these rough times can help you grow and even lead to good things in a family. Helping each other, loving each other extra hard, and trying to understand each other’s feelings can make you all feel closer.
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It’s hard to have a brother or sister with cancer. It affects you and your whole family, too. Here we will talk about how you might feel and what you can do about it.

For cancer information, day-to-day help, and emotional support, visit the American Cancer Society website at www.cancer.org or call us at 1-800-227-2345. We’re here when you need us – 24 hours a day, 7 days a week.
This Booklet Is For You.

If your brother or sister has cancer, this booklet is for you.

In this booklet you will:

→ Hear from other teens who—like you—have a brother or sister with cancer

→ Find out what has helped them

→ Get ideas about people to talk with when you’re upset or feel all alone

→ Learn a little about cancer and how it’s treated.

This booklet can’t give you all the answers, but it can help you prepare for some of the things you might face.

There is a team of people working hard to help your brother or sister get better. You should know that there are also many people available to help you. No one should go through this alone.

Free copies of this booklet are available from the National Cancer Institute (NCI). To learn more about cancer or to request this booklet, visit NCI's Web site (www.cancer.gov). You can also call NCI's Cancer Information Service at 1-800-4-CANCER (1-800-422-6237) to order the booklet or talk with an information specialist.
How To Use This Booklet

You may want to read the booklet from cover to cover. Or maybe you’ll just read those sections that interest you most. Some teens pull out the booklet now and again when they need it. You may want to share this booklet with others in your family. It might help you bring up something that has been on your mind. You could ask people in your family to read a certain chapter and then talk about it together.

We’ve put words that may be new to you in bold. Turn to the glossary at the end of this booklet for their definitions.

Wherever you go,
go with all your heart.

—Confucius
tell me what's going on.
Is there anything I can do to help you out?
Talking about what’s going on is hard. I know it’s not easy to ask questions, but is there anything you want to talk about or know?
Chapter 1

You’ve Just Learned That Your Brother or Sister Has Cancer

You’ve just learned that your brother or sister has cancer. You may have a lot of emotions—feeling numb, afraid, lonely, or angry. One thing is certain—you don’t feel good.

“For now, try to focus on these facts:

→ **Many kids survive cancer.** You have good reason to be hopeful that your brother or sister will get better. Today, as many as 8 in 10 kids diagnosed with cancer survive their illness. Many go on to live normal lives. That’s because scientists are discovering new and better ways to find and treat cancer.

→ **You’re not alone.** Right now it might seem like no one else in the world feels the way you do. In a way you’re right. No one can feel exactly like you do. But it might help to know that there are other kids who have a brother or sister with cancer. Talking to others may help you sort out your feelings. Remember, you are not alone.

“This is so unreal. I thought only old people got really sick—not little kids. My brother Jason has cancer, and he is only 10 years old. We found out last week, and it hasn’t even sunk in yet. I wake up every morning thinking this is just a bad dream.” —Liza, age 15
You’re not to blame. Cancer is a disease with many causes, many of which doctors don’t fully understand. But your brother or sister did not get cancer because of anything you did, thought, or said.

You can’t protect, but you can give comfort. Sometimes you’ll be strong for your brother or sister, and sometimes your brother or sister will be strong for you. It’s okay to talk about how hard it is and even cry together.

Knowledge is power. It can help to learn more about cancer and cancer treatments. Sometimes what you imagine is actually worse than the reality.

The gem cannot be polished without friction, nor man perfected without trials.

—Chinese proverb
Your Feelings

As you deal with your sibling’s cancer, you may feel lots of different emotions. Some of the emotions you may feel are listed below.

Check off all the feelings you have today:

☐ My world is falling apart.
☐ I’m afraid that my brother or sister might die.
☐ I’m afraid that someone else in my family might catch cancer. (They can’t.)

I feel scared because:

__________________________

It’s normal to feel scared. Some of your fears may be real. Others may be based on things that won’t happen. And some fears may lessen over time.

☐ I feel guilty because I’m healthy and my brother or sister is sick.
☐ I feel guilty when I laugh and have fun.

I feel guilty because:

__________________________

You might feel guilty about having fun when your sibling is sick. This shows how much you care about them. But you should know that it is both okay and important for you to do things that make you happy.
I am mad that my brother or sister is sick.

I am angry at God for letting this happen.

I am angry at myself for feeling the way I do.

I am mad because I have to do all the chores now.

**I am angry because:**

Anger often covers up other feelings that are harder to show. If having cancer in your family means that you can’t do what you like to do and go where you used to go, it can be hard. Even if you understand why it’s happening, you don’t have to like it. But, don’t let anger build up inside. Try to let it out. And when you get mad, remember that it doesn’t mean you’re a bad person or you don’t love your sibling. It just means you’re mad.

“Sometimes, I feel mad at my brother for having cancer. I know that’s not right, and he can’t help it. But it has changed everything. My mom and dad don’t talk about anything but him, and neither does anyone else. It’s just not fair.”

—Tyree, age 13
“At night both my parents go in my sister’s room to talk and be with her. I’m the youngest, and I need them, too. Do they both have to be with her every night?”

—Sarah, age 14

Neglected

- I feel left out.
- I don’t get any attention any more.
- No one ever tells me what’s going on.
- My family never talks anymore.

I feel neglected because:

When your brother or sister has cancer, it’s common for the family’s focus to change. Your parents don’t mean for you to feel left out. It just happens because so much is going on. You may want to tell your parents how you feel and what you think might help. Try to remember that you are important and loved and that you deserve to feel that way, even though you might not get as much attention from your parents right now.
Lonely

My friends don’t come over anymore.

My friends don’t seem to know what to say to me anymore.

I miss being with my brother or sister the way we used to be.

I feel lonely because:

We look at some things that may help you deal with changes in friendships in Chapter 9, and at things others have done to stay close to their siblings in Chapter 7. For now, try to remember that these feelings won’t last forever.

Embarrassed

I’m sometimes embarrassed to be out in public with my sibling because of how they look.

I feel silly when I don’t know how to answer people’s questions.

I feel embarrassed because:

It can help to know that other teens also feel embarrassed. So do their siblings. In time it gets easier, and you will find yourself feeling more comfortable.
Jealous

I’m feeling upset that my brother or sister is getting all the attention.

I feel jealous because:

Even if you understand why you are getting less attention, it’s still not easy. Others who have a brother or sister with cancer have felt the same way. Try to share your feelings with your parents and talk about what you think might help.

What You’re Feeling Is Normal

There is no one “right” way to feel. And you’re not alone—many other teens in your situation have felt the same way. Some have said that having a brother or sister with cancer changes the way they look at things in life. Some even said that it made them stronger.

“I feel so bad for my big sister. She’s sick all the time. She used to be the one I looked up to, and now everything has changed. Now, she looks to me for support. I feel like I’m having to grow up so fast.” —Riley, age 12
Dealing With Your Feelings

A lot of people are uncomfortable sharing their feelings. They ignore them and hope they’ll go away. Others choose to act cheerful when they’re really not. They think that by acting upbeat they won’t feel sad or angry anymore. This may help for awhile, but not over the long run. Actually, holding your feelings inside can keep you from getting the help that you need.

Try these tips:

→ **Talk** with family and friends that you feel close to. You owe it to yourself.

→ **Write** your thoughts down in a journal.

→ **Join a support group** to meet other kids who are facing some of the same things you are. Or meet with a counselor. We’ll learn more about these options in Chapter 10.

It is probably hard to imagine right now, but, if you let yourself, you can grow stronger as a person through this experience.
When you come to the end of your rope, tie a knot and hang on. —Franklin D. Roosevelt

“When my dad comes home from being with my sister at the hospital all day, he is so grumpy. One day I just asked him why he always seemed so mad at me. He got quiet and said he’s so worried and stressed that even little things set him off . . . and that being on edge isn’t fair to me and my other sister. Hearing what was going on inside my dad’s head made me realize how tough this whole situation is for him, too. It made me feel a lot closer to him, instead of so alone and mad.” —Kevin, age 15

“It’s a pain to do the dishes by myself all the time. Before he got sick it was my brother’s job to wash and my job to dry. We had a system.” —Justin, age 17

“I had to give up going to drill team after school because I had to be home to take care of my little sisters while Mom took Jay to the doctors.” —Becky, age 16
“I was so scared when I found out that my brother had cancer. In the movies cancer always seems so terrible. Then I realized that I didn’t really know that much about cancer. I started reading and learned a lot. I found out that most kids survive cancer.”
—Rashid, age 14
Learning About Cancer

Learning about cancer and your brother’s or sister’s treatment can help you feel less afraid. Some of what you have seen or heard about cancer may not apply. Most people feel better when they know what to expect.

Here are a few facts to remember:

- Nothing you did, thought, or said caused your brother or sister to get cancer.
- You can’t catch cancer from another person.
- Scientists are finding many new and better ways to find and treat cancer.
- Most kids survive cancer.

“I got really mad at Chrissy one day. She wouldn’t let me ride her bike. I got mad and said, ‘I wish you were dead.’ Now she has leukemia. I thought maybe it was my fault. I was scared to tell anyone because then they’d all know what I did and be mad. But my dad heard me crying one night, and got me to talk to him. He said it wasn’t my fault or anybody’s that Chrissy has cancer.”

—Katie, age 13
What Is Cancer?

Doctors have found more than 100 different types of cancer. Cancer is a group of many related diseases that begin in cells, the body’s basic unit of life. To understand cancer, it’s helpful to know what happens when normal cells become cancer cells.

Normally, cells grow and divide to make more cells only when the body needs them. This orderly process helps to keep the body healthy. Sometimes, however, cells keep dividing when new cells aren’t needed. These extra cells form a mass of tissue, called a growth or tumor. Tumors can be benign or malignant:

- **Benign tumors aren’t cancerous.** They can often be removed and don’t spread to other parts of the body.

- **Malignant tumors are cancerous.** Cells in these tumors are abnormal and divide and grow without control or order. They can invade and damage nearby tissues and spread to organs in other parts of the body. The spread of cancer from one part of the body to another is called metastasis.
Most cancers are named for the organ or type of cell in which they begin. For example, cancer that begins in the bone is called bone cancer. Some cancers do not form a tumor. For example, \textit{leukemia}, which is the most common cancer among children, is a cancer of the \textit{bone marrow} and blood.

\section*{Why Do Children Get Cancer?}

The causes of most cancers aren’t known. Cancer among children does not happen that often. Scientists are still trying to learn more about why some kids get cancer and others don’t.

\section*{Will I Get Cancer, Too?}

If you are worried that you may get cancer, you should know that most cancers don’t run in families. You and your parents can talk to a doctor for more information.

\section*{Can Doctors Cure Cancer?}

\textbf{Every year scientists discover better ways to treat cancer.} That means many people are successfully treated for cancer. However, doctors are careful not to use the word “cure” until a patient remains free of cancer for several years. Cancer treatment may cause a \textit{remission}, which means that the doctor can’t find signs of cancer. But sometimes the cancer comes back. This is called a \textit{relapse} or \textit{recurrence}. Whether your brother or sister will be cured of cancer depends on many things. No booklet can tell you exactly what to expect. It is better to talk with your parents and your sibling’s doctor or nurse.
Where to go for more information

To learn more about the type of cancer your brother or sister has, visit the National Cancer Institute’s (NCI) Web site (www.cancer.gov). You can also call NCI’s Cancer Information Service at 1-800-4-CANCER (1-800-422-6237) to talk with an information specialist. All calls are free and confidential.

He who is not everyday
conquering some fear
has not learned
the secret of life.

—Ralph Waldo Emerson
Chapter 3

Cancer Treatment

You may want to know what to expect during your brother’s or sister’s cancer treatment. This chapter briefly explains different treatments. It talks about how they work and their side effects. You will probably have more questions after reading this chapter. It may help to talk with your parents. Or ask if you can talk with your sibling’s nurse or social worker.

“Rachel had all this beautiful hair. But during treatment, she’d wake up and find hair all over her pillow. It would also fall out when she combed or washed it. I could hear her crying in the bathroom. One day Mom helped her shave her head. Then we bought and decorated some bandanas together. They look good on her. My sister is my hero.”

—Lauren, age 12
How Does Treatment Work?

Cancer treatment aims to get rid of cancer cells. The type of treatment your brother or sister will be given depends on:

- The type of cancer
- Whether the cancer has spread
- Your sibling’s age and general health
- Your sibling’s medical history
- Whether the cancer is newly diagnosed or has recurred.

Remember that there are more than 100 different types of cancer, and each type is treated differently.

Treatment follows a protocol, which is a treatment plan. But even if two people have the same type of cancer and the same treatment plan, it may not work the same way for both of them. This is because people’s bodies can react differently to treatment. Most children with cancer are treated at large pediatric cancer centers in clinical trials. A clinical trial is a study that helps show how, for example, a promising anticancer drug, a new test, or a possible way to prevent cancer affects the people who receive it.
What Are Treatment Side Effects?

Side effects happen because the cancer treatment targets fast-growing cells. Cancer cells are fast growing, but so are normal cells like the ones in the digestive tract and hair, for example. The treatment can’t tell the difference between fast-growing normal cells and fast-growing cancer cells. That’s why people sometimes get sick to their stomach and lose their hair when they have chemotherapy (one type of cancer treatment).

Some side effects, like feeling sick to the stomach, go away shortly after treatment, while others, like feeling tired, may last a while after treatment has ended.

Write down what treatment your brother or sister will get:

______________________________________________________________________________
______________________________________________________________________________
______________________________________________________________________________
______________________________________________________________________________
______________________________________________________________________________
______________________________________________________________________________

Use the chart on the next two pages to find out more about different types of cancer treatment.

The chart describes six types of cancer treatment, how they’re done, and some of the side effects. Your brother or sister may get one or more of these treatments. Depending on the exact treatment, they may visit the doctor during the day, or they may stay overnight in the hospital.
### TREATMENT CHART

<table>
<thead>
<tr>
<th>Treatment</th>
<th>What is it?</th>
<th>How is it done?</th>
<th>What may happen as a result? (side effects)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Surgery</strong></td>
<td>The removal of all or part of a solid tumor</td>
<td>A surgeon operates to remove the cancer. Drugs are used so that the patient is asleep during surgery.</td>
<td>• Pain after the surgery</td>
</tr>
<tr>
<td>Also called an operation</td>
<td></td>
<td></td>
<td>• Feeling tired</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>• Other side effects, depending on the area of the body and the extent of the operation.</td>
</tr>
<tr>
<td><strong>Radiation therapy</strong></td>
<td>The use of high-energy rays or high-energy particles to kill cancer cells and shrink tumors</td>
<td>Radiation may come from a machine outside the body or from radioactive material placed in the body near the cancer cells.</td>
<td>• Feeling tired</td>
</tr>
<tr>
<td>Also called radiotherapy</td>
<td></td>
<td></td>
<td>• Red or blistered skin</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>• Other side effects, depending on the area of the body and the dose of radiation.</td>
</tr>
<tr>
<td><strong>Chemotherapy</strong></td>
<td>The use of medicine to destroy cancer cells</td>
<td>The medicine can be given as pills, through an injection (shot), or through an intravenous (IV) line. It is often given in cycles that alternate between treatment and rest periods.</td>
<td>• Feeling sick to the stomach or throwing up</td>
</tr>
<tr>
<td>Also called chemo</td>
<td></td>
<td></td>
<td>• Loose bowel movements or not being able to go to the bathroom</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>• Hair loss</td>
</tr>
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<td></td>
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<td>• Feeling very tired</td>
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<td></td>
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<td>• Mouth sores</td>
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<td></td>
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<td>• A feeling of numbness, tingling, or burning in the hands and feet.</td>
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<tr>
<td>Treatment</td>
<td>What is it?</td>
<td>How is it done</td>
<td>What may happen as a result? (side effects)</td>
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<tr>
<td><strong>Stem cell transplantation</strong></td>
<td>The use of <strong>stem cells</strong> found in either the bone marrow or the blood. This repairs stem cells that were destroyed by high doses of chemo and/or radiation.</td>
<td>Stem cell transplantation uses stem cells from the patient or from <strong>donors</strong>. In many cases, the donors are family members. The patient gets these stem cells through an IV line.</td>
<td>• The side effects can be much like those from chemo and radiation. In some cases, the side effects may be worse.</td>
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</table>
| **Hormone therapy**                     | A treatment that adds, blocks, or removes **hormones** from the body. Hormone therapy is especially useful to slow or stop the growth of some types of cancers. | Hormone therapy can be given as a pill, through an injection, or through a patch worn on the skin. Sometimes surgery is needed to remove the glands that make specific hormones. | • Feeling hot  
• Feeling tired  
• Weight changes  
• Mood changes. |
| **Biological therapy**                  | Biological therapy uses the body’s own defense system (the **immune system**) to fight cancer cells. | Patients may be given medicine in pills, through an injection, or through an IV line. | • Chills/fever  
• Muscle aches  
• Weakness  
• Feeling sick to the stomach or throwing up  
• Loose bowel movements. |

Your brother or sister will get tests to monitor the cancer and how the treatment is working. See **Chart A** in the back of this booklet for a list of some common monitoring tests.
Things To Look For
Some treatments may make your brother or sister more likely to get an infection. This happens because cancer treatment can affect the white blood cells, which are the cells that fight infection. An infection can make your brother or sister sicker. So your sibling may need to stay away from crowded places or people who have an illness that he or she could catch (such as a cold, the flu, or chicken pox).

Because of this, you may need to:

- Wash your hands with soap and water often to keep from spreading germs
- Tell a parent when you’ve been around someone who’s sick or has a cold
- Stay away from your brother or sister if you get sick.

The Waiting
It’s hard to wait to see how well the treatment will work. Your brother’s or sister’s doctor may try one treatment, then another. One day your brother or sister may feel a lot better, and the next day or week they may feel sick again. Treatment can go on for months or sometimes years. This emotional roller coaster is hard on everyone.

During this time, remember that the treatment is working to stop the cancer and make your brother or sister better. For more information about the people who will be treating your brother or sister, see Chart B in the back of this booklet.
Want To Visit?

Close to home
If your brother or sister is in a hospital near you, you may be able to visit. Learn ahead of time how your sibling is doing and what to expect. You can read together, draw, play games, or sit and talk. Some teens also want to help care for their brother or sister. Ask the nurse what you can do if you are interested.

Far from home
When your brother or sister is getting treatment far from home, you may not be able to visit them as often. It will help you both to stay in touch. Talk on the phone. You can also send cards, letters, or pictures back and forth.

“I looked forward to the times I got to visit my big sister when she was in the hospital. Sometimes it was really sad to see Tara in bed because she looked so weak. But I am glad I went. Now my sister is home, so I get to see her again.” —Allie, age 14
Your Own Ups and Downs During Treatment

During your brother’s or sister’s treatment, you may go through a whole new range of feelings.

Does this sound like how you feel sometimes?

- I feel frustrated.
- I feel left out.
- I feel invisible—my sibling is getting all the attention.
- I feel like treatment has gone on so long.
- I am so sad that my sibling is so sick.
- I wonder why this is happening to our family.
- Some days I want to know all the details about treatment. Other days I just want to forget it ever happened.

All of these feelings are natural. Try to share your thoughts with your friends, parents, or another trusted adult. This time can be tough on every member of your family. Talking things through can help when you are feeling left out, sad, or confused.
Where to go for more information

To learn more about cancer treatments, visit the NCI Web site (www.cancer.gov). Look for the booklets *Chemotherapy and You,* and *Radiation and You,* among others. You can also call the NCI’s Cancer Information Service at 1-800-4-CANCER (1-800-422-6237) to talk with an information specialist. All calls are free and confidential.

“One day I went to the clinic with my brother for his treatment. I saw the machine that he gets radiation from. I got to meet his doctor and nurses and see lots of other kids with cancer. I still wish Jake’s treatment was over, but I feel better knowing more about what is going on.” —Matthew, age 15
Where Do Kids Get Treated for Cancer?

Most kids get treated at cancer treatment centers that are just for children and teens. There may be a center near you. Or your brother or sister may have to get treatment in another city or state. Your parent and your sibling, or your whole family, may go live in a new city during treatment.

Who Can Answer My Other Questions?

Ask your parents or another trusted adult any questions that you have. Ask if you can go along and maybe talk with a doctor or nurse when your parents take your brother or sister to the doctor.

To make things easier:

- Make a list of questions and bring the list with you.
- Ask people to explain things using simple words.
- Ask for the information to be repeated.
- Ask the doctor or nurse to show you things on a model or draw a picture.

“At first I didn’t ask any questions, although I had a lot of them. I thought people would think I was really dumb, but now I know it really helps to ask.” — Brad, age 15
Questions you might want to ask

→ What kind of cancer does my brother or sister have?

→ Will my brother or sister get better?

→ What are the chances I will get this kind of cancer, too?

Questions about the treatment

→ What kinds of treatment will my brother or sister get? Will there be more than one?

→ How do people feel when they get this treatment? Does it hurt?

→ How often is this treatment given? How long will it last?

→ Does the treatment change how people look, feel, or act?

→ What happens if the treatment doesn’t work?

→ Where are treatments given? Can I come along?

Write down your own questions:

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________________________________________________________________________

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It’s okay to ask these questions more than once.
"I was surprised to find out about stem cell donation because I didn't think I would have any role in my sister's treatment. So when I was asked to be a donor, I felt like it was a chance to help her in an important way. At first I had a lot of questions. A nurse was the person that helped me the most."

—Ethan, age 17
Chapter 4

Becoming a Stem Cell Donor

In Chapter 3 we listed bone marrow transplantation (BMT) and peripheral blood stem cell transplantation (PBSCT) as possible cancer treatments. Only some children with cancer get these treatments. If your sibling is going to receive one of them, you may find it helpful to read this chapter. Otherwise, you can skip it.

Why Do Some Cancers Need Bone Marrow or Stem Cell Transplants?

Sometimes very high doses of chemo and/or radiation therapy are used to treat cancer. These treatments destroy cancer cells but also wipe out good cells, like stem cells.

What Are Stem Cells?

Stem cells make the blood cells needed to carry oxygen to all the parts of the body (red blood cells), fight infection (white blood cells), and prevent bleeding (platelets). Most are found in the bone marrow—the spongy material that fills the inside of bones. Some are also found in the bloodstream.

How Transplants Work

Healthy stem cells collected from a brother or sister are transplanted into the sibling with cancer. The stem cells travel to the bone marrow and make new red blood cells, white blood cells, and platelets. These new cells help your brother or sister recover from the cancer treatments.

where you are. —Theodore Roosevelt
Who Can Be a Donor?

A stem cell donor can be a brother or sister or a volunteer (from the National Marrow Donor Program®). Stem cells can also be collected from the patient’s own body prior to cancer treatment and stored for later use.

Facts about donors:

- A donor is a person whose stem cells match those of the person with cancer. Not everyone is a match.
- A patient’s brother or sister is more likely to match than someone who is not related.
- In one out of four cases, a brother or a sister is a good match.
- When no one in the family is a match, the medical team can look for a volunteer donor from around the world.

Thoughts From Teens Who Were Donors

- “I was scared. No doubt about it—the thought of being a donor made me nervous ‘til I knew what was going to happen.”
- “I didn’t feel like I had a choice until my parents said it was up to me to decide if I wanted to do this or not.”
- “I felt my big brother and my whole family were counting on me for this to work. I am glad that it did!”

Courage is the first of human qualities because it is
What If I’m Asked To Be a Donor?

If you agree to be a donor, the doctor will do a special blood test to find out whether you are a match for your brother or sister. The test will show whether your stem cells are a good match or not.

What If I’m Not a Match?

You may be tested and find out that you are not a match. You may feel disappointed or that you are letting your brother or sister down. It’s important to know that it’s not your fault if you are not a match. While it’s natural for your family to feel down, no one should be upset with you.

“I was so disappointed that neither my sister Heather or I were a match for our little sister Taylor who has cancer. No one blamed us—but it was still hard. Now the doctors are trying to find a match from other donors.” —Caitlin, age 13

the quality which guarantees the others. —Aristotle
Don’t be afraid to ask questions about anything that you don’t understand or feel comfortable about. Write down some of your questions:

<table>
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<th>Question 1</th>
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<td>Question 2</td>
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<td>Question 4</td>
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<tr>
<td>Question 5</td>
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</tbody>
</table>

“The doctor told me I was a match for my brother Chris. My mom said it was my choice—I did not have to be a donor if I didn’t want to. But even though I was kind of nervous, I wanted to do it. Chris’s doctor met with us to explain what would happen. I hope this will help my brother.” —Amber, age 15
“It didn’t hurt as much as I thought it would to be Jada’s donor. Before I knew it, I was playing softball again. My advice to other kids who want to be donors is to ask questions—lots of them. It would have helped me to be more prepared. I really didn’t know what to expect.”
—Anthony, age 16

What happens during the transplant?

**For a bone marrow transplantation (BMT),** the doctors collect stem cells from your bone marrow. Before the doctor collects the stem cells, you will get medicine to help you fall asleep. Then the doctor will put a needle into your hip bone to collect the bone marrow. You won’t feel pain from the needle because you will be asleep. Afterwards, you may be a little stiff or sore for a couple of days at the place where the needle went in.

**For a peripheral blood stem cell transplantation (PBSCT),** the doctors collect stem cells from your blood. A doctor will take blood from you, usually through a vein in your arm. Your blood will go through a machine that removes the stem cells. Then your blood is put back into you. The stem cells are stored and later given to your sibling through a **transfusion.**
What If the Transplant Doesn’t Work?

No one can guarantee that the transplant will make your sibling get better, but the chance to help your brother or sister can be very rewarding. It can help you feel more involved. However, it can be difficult if the transplant doesn’t work. Know that it wasn’t your fault. You did what you could, and no one should blame you.

“I turned out to be a match for my brother David. The bad news was that the transplant didn’t help my brother. I felt like I had really let him down. But David told me not to feel bad about it. He told me how much it meant to him that I even gave it a try.”
—Jason, age 15

What about other questions that I have?

Ask any questions that you have. Doctors, nurses, and social workers can all help you. So can your parents. Your family can also get more information from the National Marrow Donor Program®. It is an organization that keeps a list of volunteer donors and transplant centers. Call 1-800-MARROW-2 (1-800-627-7692) or go to www.marrow.org.
Chapter 5

What Your Brother or Sister May Be Feeling

Just like everyone else, your brother or sister may be worried, scared, or confused. They may also feel tired and sick because of the treatment. Some kids feel embarrassed because treatment has changed the way they look and feel. You both may be having a lot of the same feelings.

Look at the World Through Your Brother’s or Sister’s Eyes

Knowing how your brother or sister might be feeling could help you figure out how to help, or at least understand where they are coming from.

Here are a few things young people with cancer have felt:

<table>
<thead>
<tr>
<th>Afraid</th>
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<td>Depending on how old your brother or sister is and how they react to tough situations, they may be more or less afraid.</td>
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“T’s scary to learn that you have cancer. Will the treatment hurt? Who are all these doctors and nurses prodding at me and asking me questions? I don’t like not knowing what will happen. I don’t like not knowing if I will get better.” —Tamara, age 13
Sad or Depressed

People with cancer sometimes can’t do things they used to do. They may miss these activities and their friends. Feeling sad or down can range from a mild case of the blues to depression, which a doctor can treat.

“I hate it that I can’t do a lot of the things I used to do. I miss hanging out with my friends. I never thought I would say this, but I even miss school. A lot of the time I just don’t want to talk at all, and when I do, I can’t be cheerful and happy all the time.”
—Ryan, age 15

Angry

Cancer and treatment side effects can cause your brother or sister to be mad or grumpy. Anger sometimes comes from feelings that are hard to show, like being afraid, being very sad, or feeling helpless. Chances are your sibling is angry at the disease, not at you.

“I admit it. I am not nice a lot of days. I feel ticked off. People get on my nerves. I’m like—why is this happening to me? Some days I just feel mad about everything.”
—Jeremy, age 16
“Everything is different now that I have cancer. It’s like the whole family just stopped doing what they were doing. I know my sisters can’t be happy about that. They have to do all the chores. My older sister had to stop cheerleading so she could take care of my little sister after school. I feel guilty that I brought this on.” —Nicole, age 14

Guilty
Your brother or sister may feel guilty that they caused changes in your family’s life. But just as you did not cause this situation to happen, neither did your brother or sister.

Hopeful
There are many reasons for your brother or sister to feel hopeful. Most kids survive cancer, and treatments are getting better all the time. Hope can be an important part of your brother’s or sister’s recovery.

“I keep the faith. I put up a huge sign in the living room that says ‘If you have to be blue, be a bright blue.’ My three brothers and I used all these blue colored markers and we decorated it with glitter. I have to keep believing that I will get cured. It is what keeps me going.” —Julie, age 16

All of these feelings are normal for a person living with cancer.
You might want to share this list with your sibling. Ask them how they are feeling.
Dear Diary,

What is going on? Everything is changing so fast. Six months ago I was the little sister ready to start high school. Now I am the most adult one in the family. Since Jill got sick, Mom is a mess—sad and stressed all the time. She thinks we don’t see, but we do. All our time is spent going to Jill’s doctor visits. Dad works day and night and all Jill does is lie around and listen to music. I know the cancer makes her mad, but does she have to shut me out? Is my family ever going to get back to normal again?

—Beth, entry from September 18th
Chapter 6

Changes in Your Family

Changing Routines and Responsibilities

Your family may be going through a lot of changes. You may be the oldest, youngest, or middle child in your family. You may live with one parent or two. Whatever your family situation, chances are that things have changed since your brother or sister got sick. This chapter looks at some of these changes and ways that others have dealt with them.

Does this sound like your home?

- Are you doing more chores?
- Are you spending more time with relatives or friends?
- Are you home alone more?
- Are you asked to help make dinner or do the laundry?
- Are you looking after younger brothers or sisters more?
- Do you want to just hang out with your friends when you are needed at home?
Does this sound like you?

→ Do you feel like you have to be perfect and good all the time?
→ Do you try to protect your parents from anything that might worry them?
→ Do you feel like yelling, but hold it in because you don’t want to cause trouble?

No one can be perfect all the time. You need time to feel sad or angry, as well as time to be happy. Try to let your parents and others you trust know how you’re feeling—even if you have to start the conversation.
Your Relationship With Your Parents

Your parents may ask you to take on more responsibility than others your age. Your parents may be spending more time with your brother or sister. You might resent it at first. Then again, you may grow and learn a lot from the experience. See Chapter 10 for tips on talking with your parents.

Touching Base When Things Are Changing

Families say that it helps to make time to talk together—even if it’s only for a short time each week. Talking can help your family stay connected. Here are some things to consider when talking with:

**Other brothers and sisters**

- If you are the oldest child, your younger brothers or sisters may look to you for support. Help them as much as you can. It’s okay to let them know that you are having a tough time, too.

- If you are looking to your older brother or sister for help, tell them how you are feeling. They can help, but they may not have all the answers.

**Try saying something like this:**

I’m doing the best job I can. How can we work together to get through this?
When the drumbeat changes,

**Your parents**

- Expect your parents to feel some stress, just like you may. Your parents may not always do or say the right thing.

- Try to make the most of the time you do have with your parents. Let them know how much it means to you. Maybe you can go out to dinner together, or they can come to your sports game, from time to time.

- Sometimes you may have to take the first step to start a conversation. You may feel guilty for wanting to have your needs met—but you shouldn’t. You are important and loved, too.

- Keep talking with your parents, even though it may be hard.

**Try saying something like this:**

- **Dad,** I have something to say. Is this a good time to talk?
- **Mom,** we need to talk. Have a minute?
the dance changes. —Nigerian proverb

You may want to try saying something like this:

**IS THERE ANYTHING I CAN DO TO HELP YOU OUT?**

---

**Your brother or sister with cancer**

→ Your brother or sister may be sick from the treatment and want to be alone. Or maybe they feel okay and want your company.

**Try saying something like this:**

**WANT TO PLAY A GAME—OR TALK?**
“I just wasn’t ready for all these changes. My sister Kelly and I had always shared a bedroom. But when she got sick, she got the bedroom because Mom and Dad had to keep coming in during the night. Some nights I had to sleep on the couch in the living room. My brother Tim and I can’t even have friends over as much anymore because they could bring germs when Kelly is sick. It’s very different now.” —Jessica, age 13

Keeping the Conversation Going

If you’re used to talking openly at home, you might find that your parents aren’t sharing as much anymore.

Maybe they’re trying to protect you from bad news or unsure about what to tell you. Some teens want to know a lot, while others only want to know a little. Tell your parents how much you want to know.
Over the next few weeks or months, you may overhear parts of your parents’ conversations. If what you hear confuses or scares you, talk with your parents about what you heard.

**Keeping Family and Friends in the Loop**

**Challenge**

It’s getting to be too much to answer the phone all the time and tell people how your brother or sister is doing.

**Solution**

Ask others to help you share news of how your brother or sister is doing. Maybe a relative or family friend can be the contact person and help let others know how your brother or sister is doing. Some families use a Web site or e-mail listserv to share this information.

**Getting Help When You Need It**

**Challenge**

Your family can’t keep up with the house, meals, and other activities.

**Solution**

Friends and neighbors often want to help make meals, clean, drive, or look after you and your siblings. Make a list with your parents of what needs to get done. Keep the list by the phone. When people ask what they can do to help, pull out the list.
Growing Stronger as a Family

Some families can grow apart for a while when a child has cancer. But there are ways to help your family grow stronger and closer. Teens who saw their families grow closer say that it happened because people in their family:

- **Tried** to put themselves in the other person’s shoes and thought about how they would feel if they were the other person.

- **Understood** that even though people reacted differently to situations, they were all hurting. Some cried a lot. Others showed little emotion. Some used humor to get by.

- **Learned** to respect and talk about differences. The more they asked about how others were feeling, the more they could help each other.

“*My family wasn’t really close before my sister Gina got cancer. We used to go our own way and never did much together. When Gina got sick, we started pulling together more. We talked to our pastor about how much more each day meant. Now it seems like even simple things are special—like eating dinner together as a family.*”

“We all acted differently when my middle brother Terrell got cancer. My younger brother started acting like a baby again and my older brother never seems to be home. I’m the only girl and feel like I have to hold it all together for my whole family.” —Keisha, age 14
The past cannot be changed; the future is still in your power —Hugh White

**Asking Others for Help**

You and your family may need support from others. It can be hard to ask. Yet most of the time people really want to help, so don’t hesitate to ask.

“Brian and I are not just brothers, we’re best friends. When he got sick, it was so hard for me that I didn’t feel like doing anything or talking to anyone. I felt down a lot, but I didn’t let anyone know. Being at home wasn’t much fun because Brian was always so sick. My math teacher noticed that I was different and asked me what was up. It’s been good to have someone I can go to when I need to get things off my chest.”

—Mike, age 18
People that you or your parents may ask for help:

- Grandparents, aunts, and uncles
- Family friends
- Neighbors
- Teachers and coaches
- People from your religious community
- Your friends and their parents
- School nurses and guidance counselors.

Ways people can help you:

- Help with homework.
- Talk with you and listen to you.
- Give rides to school or practice.
- Invite you over or on weekend outings.

Other things people can do to help around the house:

- Buy groceries or run errands.
- Make meals.
- Mow the lawn.
- Do chores around the house.

What are some other ways that people can help you?
List some ideas here:
Chapter 7

How You Can Help Your Brother or Sister

This chapter has some things that others have done to help their brother or sister. Pick one or two things you may want to try this week. Then pick a couple more next week.

“People used to call Jessie and me ‘the twins!’ We are 13 months apart, but we look so much alike and we were always together. Now that Jess has cancer she’s lost all her hair and —well, unfortunately, people can tell us apart. Last week I decided to do something pretty drastic to show my sister how much I love her. I shaved my head! Now, I am not saying that is the right thing for all sisters to do—but it felt like the right thing for us.” —Renee, age 15
Help by Just Being There

→ **Hang out together.** Watch a movie together. Read or watch TV together. Decorate your brother’s or sister’s bedroom with pictures or drawings. Go to the activity room at the hospital and play a game or do a project together.

→ **Comfort one another.** Just being in the same room as your brother or sister can be a big comfort. Do what feels best for the two of you. Give hugs or say “I love you.” Laugh or cry together. Talk to one another. Or just hang out in silence.
Help by Being Thoughtful

→ **Help your brother or sister stay in touch with friends.** Ask your sibling’s friends to write notes, send pictures, or record messages. Help your brother or sister send messages to their friends. If your brother or sister is up for it, invite friends to hang out with them.

→ **Share a laugh.** You’ve probably heard that laughter is good medicine. Watch a comedy or tell jokes together, if that is your thing.

→ **Be patient.** Be patient with each other. Your brother or sister may be cranky or even mean. As bad as you feel, your brother or sister is probably feeling even worse. If you find you are losing your cool, go for a run, read, or listen to music.

→ **Make a snack.** Make a snack for the two of you to share. Make a picnic by putting a blanket on the porch or in the bedroom.

→ **Buy a new scarf or hat.** Your brother or sister might like a new hat or scarf if they have lost their hair during treatment. Get a matching hat or scarf for yourself, too.

→ **Try to be upbeat, but be “real,” too.** Being positive can be good for you and your whole family. But don’t feel like you have to act cheerful all the time if that’s not how you really feel. Try to be yourself.

---

I am only one, but I am one.

I cannot do everything,

but I can do something.

—Edward Everett Hale
Help by Staying Involved

➔ **Keep a journal together.** Write thoughts or poems, doodle, or put photos in a notebook. Take turns with your sibling writing in a journal. This can help you both share your thoughts when it might be hard to talk about them.

➔ **Go for a walk together.** If your brother or sister feels up to it, take a walk together. Or, open a window or sit on the front porch together.

The ideas above are for those times when you have extra energy to give. **Don’t forget to take care of yourself, too. You deserve it.** Read more about taking care of yourself in the next chapter.

**Can you think of some other ways to help your brother or sister?**

Make your own list here:

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____________________________________________________________________________________

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____________________________________________________________________________________

____________________________________________________________________________________
Chapter 8

Taking Care of Yourself

“When we found out my sister Kiana had cancer, we all seemed to focus on her—and nothing else. I was so worried that I stopped hanging out with friends and quit training for track meets. One day my mom said that giving up all these things wasn’t good for me. She said it was okay to have fun and practically pushed me out the door to start going to track again. I didn’t think anyone noticed me, but I’m glad my mom did! She even came to my next track meet!”

—Patrick, age 16
It’s Important To “Stay Fit”—Both Inside and Out

You may be so focused on your sick brother or sister that you don’t think about your own needs, or if you do, they don’t seem important. But they are! Read this chapter to learn ways to stay balanced at a time when everything may feel up in the air.

Dealing With Stress

Stress can make you forgetful, frustrated, and more likely to catch a cold or the flu. Any way you look at it, too much stress isn’t good.

Here are some tips that have worked to help other teens manage stress. In the lists on the next few pages, check one or two things to do each week.

Turn your face to the sun and the shadows fall behind you.

—Maori proverb
Take Care of Your Mind and Body

→ **Stay connected.**

- Spend some time at a friend’s house.
- Stay involved with sports or clubs.
- Add your own here: __________________________

→ **Relax and get enough sleep.**

- Take breaks. You’ll have more energy and be in a better frame of mind.
- Get at least 8 hours of sleep each night.
- Pray or meditate.
- Make or listen to music.
- Add your own here: __________________________
Help others.

- Join a walk against cancer.
- Plan a bake sale or other charity event to collect money to fight cancer.
- Add your own here:

Avoid risky behaviors.

- Stay away from smoking, drinking, and other risky behaviors.

Put your creative side to work.

- Keep a journal to write down your thoughts and experiences.
- Draw, paint, or take photographs.
- Read books or articles about people who have made it through difficult experiences in life. Learn what helped them.
- Add your own here:
Eat and drink well.

- Switch to caffeine-free drinks in the evening that won’t keep you awake.
- Grab fresh fruit, whole-grain breads, and lean meats like chicken or turkey when you have a choice.
- Avoid foods that have a lot of sugar.
- Drink 6–8 glasses of water a day to help prevent fatigue.
- Add your own here:

Be active.

- Play a sport or go for a run.
- Take the dog for a walk.
- Learn about different stretching and breathing exercises.
- Add your own here:
Did you know?

Exercise has been proven to make you feel better. Running, swimming, or even walking at a fast pace can help improve your mood.

Take Steps To Keep Things Simple

Staying organized can also keep your stress level under control. Here are some tips to get you started.

➡️ At home

☐ Make a list of things you want to do. Put the most important ones at the top.

☐ Make a big calendar to help your family stay on top of things.

➡️ At school

☐ Let your teachers know what’s happening at home, without using it as an excuse.

☐ Talk to your teachers or a counselor if you are falling behind. They can help you.
“It sounds weird—since my family didn't used to be that organized—but keeping track of everything on a calendar really helped us stay on track. It made everything feel more under control—especially when things got a little crazy.” —Eric, age 17

What Else Can You Do?

The ideas listed above may help. You may also have others that would work even better. Write down your ideas below:
Get Help When You Feel Down and Out

Many teens feel low or down when their brother or sister is sick. It’s normal to feel sad or “blue” during difficult times. However, if these feelings last for 2 weeks or more and start to interfere with things you used to enjoy, you may be depressed. The good news is that there is hope and there is help. Often, talking with a counselor can help. Below are some signs that you may need to see a counselor.

Are you:

- Feeling helpless and hopeless? Thinking that life has no meaning?
- Losing interest in being with family or friends?
- Finding that everything or everyone seems to get on your nerves?
- Feeling really angry a lot of the time?
- Thinking of hurting yourself?

Do you find that you are:

- Losing interest in the activities you used to enjoy?
- Eating too little or a lot more than usual?
- Crying easily or many times each day?
- Using drugs or alcohol to help you forget?
- Sleeping more than you used to? Less than you used to?
- Feeling tired a lot?
If You Answered “Yes” To Any of These Questions...

It’s important to talk to someone you trust. Going to see a counselor doesn’t mean that you are crazy. In fact, it means that you have the strength and courage to recognize that you are going through a difficult time and need help. Read more about what teens who’ve talked with a counselor or met with a support group have to say in Chapter 10.

“It got to the point where I was feeling down all the time, like I just didn’t have any energy and nothing seemed fun anymore. I even stopped hanging out with my friends. I felt like I couldn’t tell anyone what was going on, not even my family. But then I started talking with a counselor and now things are getting back on track.” —Jake, age 17
“My grades were slipping. I wasn’t that great a student before my sister got cancer. Once she got really sick I stopped caring about school. My art teacher noticed that my drawings were different. She talked with me and helped me get an appointment with the guidance counselor. I feel like a weight’s been lifted off my shoulders. I still worry about my sister, but am doing better in school now.” —Ray, age 16
You and Your Friends

Your friends are important to you, and you’re important to them. In the past, you could tell them everything. Now that your brother or sister has cancer, it may seem like lots is changing—even your friendships. Here are some things to think about:

Some friends may not know what to say.

- It’s hard for some people to know what to say. They may be afraid of upsetting you. Try to be gentle with friends who don’t ask how you’re doing or who don’t talk about your brother’s or sister’s cancer.

- You may need to take the first step.

- Try saying something like this:

“Before my big brother Trevor got cancer, my three best friends were my life. I didn’t go anywhere without them. I was never really home. Things are different now. I still see my friends, but I want to hang out with Trevor a lot more now. I definitely don’t take him for granted anymore. My friends keep on going like nothing has changed. And for them—nothing has.” —Taylor, age 16

Talking about what’s going on is hard. I know it’s not easy to ask questions, but is there anything you want to talk about or know?
Sometimes it’s hard talking about everything that’s going on. If this was happening to one of my friends, I probably wouldn’t know what to say to them, either. It just makes me appreciate even more the friends who have called or stopped by to hang out.”

—Justin, age 16

Some friends may ask tough questions.

→ It may be hard to answer questions about what you and your family are going through. You may want to try to help your friends understand what’s going on. Or sometimes you may not feel like talking at all.

→ Try saying something like this:

THANKS FOR ASKING ABOUT MY FAMILY AND ME. HERE’S WHAT THE DOCTORS ARE SAYING: [ADD IN YOUR OWN INFORMATION HERE].

→ If you don’t feel like talking, try saying something like this:

THANKS FOR ASKING, BUT CAN WE TALK LATER?
“People asked me questions all the time. They’d say things like, ‘I heard Molly isn’t coming back to school this year’ or ‘I heard your mom was having a breakdown.’ When I told them the truth, they didn’t believe me. And they’d ask dumb questions like, ‘Can Molly walk? Can she write?’ They didn’t know what was going on, and I didn’t know how to answer them. I got sick of it.” —John, age 14

Your friends have their own lives.

→ It may feel like your friends don’t care anymore. It might seem as though their lives are moving on and yours is not. It can be hard to watch them get together with others or do things without you. They aren’t facing the situation you are right now, so it may be hard for them to relate.

→ You might want to try saying something like this:

I MISS HANGING OUT TOGETHER.
I KNOW THAT I’VE HAD A LOT ON MY MIND SINCE MY SISTER GOT SICK.
WANT TO HANG OUT TOMORROW?
“I get the feeling my friends want me to just 'get over it' and go back to how life was before we found out my sister has cancer. But I wish they understood that sometimes I just don't feel like doing what they're doing or talking about what they're talking about. I really want to spend time with my sister.”
—Max, age 15

“Now that my brother lost his hair and is so skinny, I don't want my friends to come over anymore. I don't want them to see how Tim looks. Besides, it's not easy to laugh and play at home when he's so sick.”
—Caroline, age 14

“My friends have been great. They love Emmalike she was their own sister. It helps to know that they care.”
—Angie, age 13
Dealing With Embarrassment

It may be hard to talk with your friends. You may feel embarrassed that your brother or sister has cancer, or that now your family is different. You may not want to tell anyone about it. But when someone in your family is sick, you really need friends you can talk with.

Having Fun and Making New Friends

Old friends:

Even though you may have a lot on your mind, you can still get together with your friends and have a good time. If you can’t leave home as much, ask if your friends can come over. Make time to relax. It’s both good and important for you.

Make a list of fun things you and your friends like to do together. Then do them!

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New friends:

A lot is happening to you right now. Sometimes old friends move on. You may not have as much in common as you used to. The good news is that you may make new friends through this experience. Kids who used to just pass you in the halls may now ask you how you are doing. Kids who you used to be friends with may become close friends again. Be open to new friendships.

Going to support groups at the hospital or at school is a good way to meet new friends. Support groups can help connect you with other kids who can relate to you—because they’re going through some of the same things that you are.

Dealing With Hurtful Remarks

Unfortunately, some kids may say mean things. Others speak before they think and before they get the facts. No matter the reason, it can hurt when kids make jokes or say hurtful things about you, cancer, or your brother or sister.

What can you do?

→ Ignore the comment.

→ Say, “Hey, my brother/sister has cancer. It’s not funny. How would you feel if it were your brother/sister?”

→ Being bullied? Go to your teacher, principal, or guidance counselor right away.
Chapter 10

Finding Support

Don’t let being afraid of the way you feel keep you from talking to your parents, a counselor, or kids in a support group.

For many people, starting to talk is difficult. Some teens don’t have good relationships with their parents. Others are too embarrassed to talk about personal things. It can also just be hard to make the time to talk, with all that is going on. But you and your parents really can help each other.

“Before I went to a support group I felt like my sister’s cancer was just something that I had to deal with on my own. I thought it would be dumb and depressing to talk with others who were going through the same thing as me—but it’s helped a lot! I would tell other kids to find a support group for sure. Check out more than one if you don’t like the first one you go to.”
—Devon, age 15

Tip: Don’t be shy about asking for help.

You may think: “I can solve all my own problems.” However, when faced with tough situations, both teens and adults need support from others!
Here Are Some Tips For Talking With Your Parents

Prepare before you talk.

**STEP 1**
Think about what you want to say and about some solutions to the problem.

**STEP 2**
Think about how your parents might react. How will you respond to them?

Find a good time and place.

**STEP 1**
Find a private place, whether it’s your room or the front steps. Or maybe you can talk while taking a walk or shooting hoops.

**STEP 2**
Ask your parents if they have a few minutes to talk.
Take things slowly.

**STEP 1**
Don’t expect to solve everything right away. Difficult problems often don’t have simple solutions.

**STEP 2**
Work together to find a way through these challenges. Some conversations will go better than others.

Keep it up.

**STEP 1**
Don’t think you have to have just one big conversation. Have lots of small ones.

**STEP 2**
Make time to talk a little each day if you can, even if it’s just for a few minutes.
Talking With a Counselor

Sometimes talking to friends and your parents is not enough. When you are having a hard time, it can be helpful to talk to a counselor. Friends Brice and Nick talk about what is happening in Brice’s home:

THINGS ARE A TOTAL MESS AT HOME RIGHT NOW. MY PARENTS ARE NEVER AROUND, AND WHEN THEY ARE THEY ACT LIKE I’M NOT EVEN ALIVE. EVERYTHING IS ABOUT MY BROTHER PAUL. I KNOW HE’S SICK, BUT EVERYTHING DOESN'T HAVE TO REVOLVE AROUND HIM. SOMETIMES I JUST FEEL LIKE TAKING OFF.

WHAT ARE YOU TALKING ABOUT?

I DON'T KNOW. I FEEL BAD SAYING IT, BUT I'M GETTING TOTALLY TIRED OF PAUL BEING SICK. MY DAD IS NICE TO HIM ALL THE TIME, BUT HE ALWAYS YELLS AT ME.

YOU'RE ANGRY ALL THE TIME, MAN. AND THAT CAN'T BE GOOD, BRICE.

I FEEL THAT WAY, NICK. IT'S HARD TO SLEEP, AND I DON'T EVEN FEEL LIKE EATING. IT'S ALL JUST TOO MUCH. AND THE WORST PART? I REALLY DO LOVE MY BROTHER, AND I CAN'T STAND TO SEE HIM SO SICK.

I HEAR YOU, BRICE, BUT YOU HAVE TO TALK TO SOMEONE. ALL THIS CAN'T BE GOOD. PROMISE ME YOU'LL TALK TO MR. DAVIS. HE'S THE BEST COUNSELOR AT SCHOOL.

OKAY, OKAY. YOU'RE RIGHT. I'LL LET MR. DAVIS KNOW WHAT'S GOING ON.
Why Go to a Counselor?

Remember—going to a counselor means you have the courage to recognize that you’re going through a tough time and need some help. **Simply put:** talking to a counselor can help you feel better.

Counselors are specially trained to help you sort out your feelings, gain new skills to deal with what’s going on, and find solutions that work for you. Teens who’ve talked with a counselor say it helped to talk to someone outside their circle of friends and family who didn’t take sides, who they could trust. Others say they learned a lot about themselves and felt better able to face life’s challenges.

"It took a few visits, but then I got to know and trust my counselor. She really listened to me and was like a coach who helped me learn new skills and see new ways of looking at things. I grew a lot.”

—Samantha, age 15

“I was having a really hard time dealing with my sister’s cancer. But I tried to be ‘perfect’ and pretend that everything was okay. I didn’t want to stress my parents out even more. One day my aunt said it might help to talk with a counselor—even if it seemed like I had it all together. I was nervous at first, but I went. The counselor made me feel like I could tell her anything—and I finally opened up about how I was really feeling. It felt great to just have someone focus on me and what I was going through.”

—Jen, age 16
Finding a Counselor

There are many ways to find a counselor. Here are some suggestions to get you started:

→ Talk to your parents or someone else that you trust. Let them know you would like help to get through this difficult time. Tell them that you would like to talk to a counselor. Ask for help making appointments and getting to visits. Sometimes you can even bring a friend.

→ Ask a nurse or social worker at the hospital if they can give you the name of someone you can talk to.

→ Ask your guidance counselor or school nurse if you can talk to him or her.

Joining a Support Group

A good outlet for connecting with teens that are going through the same thing that you are is a support group. Some groups meet in person; others meet online. Some groups go out and do activities together. At first this may not sound like something you want to do. Other teens have thought the same thing—until they went to a meeting. They were surprised that so many other kids felt the same way they did and had advice that really seems to work. Your parents or another trusted adult can help you find a support group.
Chapter 11

After Treatment

When your brother or sister has finally completed treatment, you and your family may feel a **whole range of emotions**. Part of you is glad it is over. Another part of you may miss the freedom or new responsibilities you had while your parent was busy taking care of your sick brother or sister.

Your brother or sister may still look sick and be weaker than you expected. You may be afraid the cancer will come back. You may be looking to find more meaning in your life now. All these feelings are normal. **Things may not go back to exactly how they were before cancer came into your lives. Getting back to your “old life” may take a long time—and it may not happen as you expect.**

“My sister Dana had to go to a cancer treatment center 6 hours away. I only got to see her two times. We talked on the phone, but it wasn’t the same. My sisters and I sent photos and letters so she knew we were thinking about her. We’re glad to have Mom and Dana back home now.” —Kyle, age 13

only one day at a time. —Abraham Lincoln
Here’s what others have said about life after treatment. Do any of these kids sound like you?

**Neil talks about the “new normal”:**

“I watched my younger brothers when Alex was away getting treatment. My stepdad counted on me since he was working and Mom was at the hospital with Alex all the time. Now that Alex is home, I’m back to being just one of the kids. Alex is getting all the attention—even from my little brothers who used to look up to me all the time. My stepdad says I’ll get used to being a kid again. But right now it doesn’t feel that way.” —Neil, age 16

**Ross appreciates life more:**

“It used to be all about having the latest stuff. If one of my friends got a new skateboard or jacket, I had to have it, too. After Jackie got sick, I realized that it was just that—stuff. Now there are more important things in life—like my sister and my family. When someone you care about is really sick, you find out what really matters.” —Ross, age 15
Tanya is glad to have her sister back home:

“Before my sister Amy got sick, we fought all the time. If she wore one of my sweaters, I was on her. It bugged me when she followed me around, especially when my friends were over. And if she got into my stuff—it was war. But after Amy got cancer things just didn't matter anymore. I was like—’take my sweater Ames—keep it, it's yours.' I realized how much I would miss her if anything happened to her.” —Tanya, age 15

Write down what life after treatment feels like for you and your family:

__________________________________________________________________________

__________________________________________________________________________

__________________________________________________________________________

__________________________________________________________________________

__________________________________________________________________________

__________________________________________________________________________

__________________________________________________________________________
What If Treatment Doesn’t Help?

If treatment doesn’t help your brother or sister, you and your family will face even more challenges. Hearing that your sibling might die is very difficult. You may feel many of the same emotions you felt when you first learned that your brother or sister had cancer.

No booklet can give you all the answers or tell you exactly how you will feel. But when the future is so uncertain, teens say that it helps to:

- **Make the most of the time you have.**
  - Do special things as a family. At home, make time for your brother or sister. Call and visit as much as you can if they are in the hospital. Write notes and draw pictures. Say “I love you” often. If possible, try to have some special times together. If you have not gotten along in the past, you may want to let your brother or sister know you love them.

- **Stay on track.**
  - When people get bad news, they often feel like they’re living outside of themselves—that life is moving along without them. That’s why it’s important to keep a schedule and stay connected. Stay involved in school. Be with friends. And let yourself take breaks from it all when you need to.

- **Have hope.**
  - Never stop believing in tomorrow, and don’t be too hard on yourself. There is more good than bad in this world—even though you might not feel that way right now.

> When it is dark enough, you can see the stars. —Ralph Waldo Emerson
Get help when you feel alone.
Make sure you find people who can help you. In addition to your family, it may help to talk to a social worker, counselor, or people in a support group. It’s important to let your feelings out.

Do you want more support and guidance?
Many cancer organizations can help you during this very difficult time in your life. Turn to Chapter 13 for information about some of these organizations.

you can see the stars. —Ralph Waldo Emerson
If Your Brother or Sister Passes Away, Know That:

You’ll always have memories.
Your brother or sister will always be part of your life. Hold on to your memories of the good times. It’s okay to think about something funny that your brother or sister did or said. By laughing and smiling you are bringing back just a little of what was so special about them.

The pain will lessen with time.
At first the pain may be so strong that you might wonder whether you will ever feel happy again. Time has a way of healing. Not being sad every day doesn’t mean that you have forgotten. It just means that you’re starting to heal.

Everyone grieves in his or her own way.
Some teens grieve for their brother’s or sister’s death by crying. Others get quiet and spend time by themselves. Some find that they need to be around friends and talk. Others get very angry. In any case, most people finds it helps to keep a regular routine. There is no right or wrong way to grieve. It’s okay to deal with loss at your own pace.

Your sibling would want you to be happy.
Stay open to new experiences. Make small changes that give your life new meaning. Write about your thoughts and about this experience. Don’t worry about what to say, just write.

Life will change.
Life won’t be the same as before, but it can be rich and full again. Keep believing this.
“We all huddled in my mom’s bed the night we found out that Gracie’s treatment wasn’t working anymore. Gracie was so wise. Even though she was only 10 years old, she was trying to comfort us and tell us it would all be okay. That made us want to cry harder—but something inside said to be brave for Gracie. Now, we look at photos and talk about Gracie. I still don’t know how life without my little sister will look. I just try to take it one day at a time.” —Gail, age 19
The journey of a thousand miles must begin with a single step.

—Lao Tzu
Chapter 12

The Road Ahead

Sometimes things do work out as you hope.

Christine shares her story:

“My brother has been in remission for two years now. Things were pretty bad at first. Then after a while, things sort of settled down and got back to the way they were before. I think Rob’s cancer brought us all closer together. I get along better with him and my sister and even with my older brother now. I’m closer to Mom and Dad. And I think we all grew up a lot while he was sick.” —Christine, age 15

Sometimes things look like they won’t work out as you hope.

Here’s what Sam has to say:

“Watching my little brother play with his cars one morning made me so sad. He loves those things. He looked up and told me if he dies I can have all his cars. Then he just went on playing. I felt a huge lump in my throat. He’s an amazing little kid.” —Sam, age 14
It can be hard to stay calm when you aren’t sure what the future holds. You may be thinking—will my brother or sister live? Will the cancer come back? Will life ever be the same? Will I laugh again? Enjoy being with friends again?

While no one can know the future, there are things you can do to make your life a little easier:

→ **Keep talking and pulling together as a family.** You may find that cancer has drawn you closer together and made you appreciate each other more.

→ **Discover your own needs.** Don’t let others tell you how you should feel. Allow yourself to cope at your own pace and in your own way.

→ **Remember that you’re growing as a person.** Many teens say that having a brother or sister with cancer has made them more sympathetic, more responsible, and stronger.

→ **Keep in mind that you aren’t alone.** Right now you may feel lonelier than you ever have in your life. But you are not alone. Family members, friends, neighbors, support groups, and counselors are there to lend a helping hand, listen to you, and give you good advice. Accept their help; you deserve it.

→ **Appreciate each day.** Many teens who have a brother or sister with cancer say that they learned to see the world more clearly. In time you may come to appreciate things you may have overlooked in the past.
Maybe you have noticed that little things seem to have more meaning for you these days. Take some time to write these thoughts down, even if they seem small:

Unfortunately, no booklet or person can tell you how everything is going to work out. Cancer is tough, and your life may never be quite the same. But in the end, you will get through it. Why? You’re strong. And you are capable—even if you don’t always feel that way.
It’s great that you want to learn more!

Keep in mind that cancer treatments are getting better all the time. Make sure that what you read or see is up to date and accurate. Talk with your parents or another trusted adult about what you find. Share the articles or books you’ve found with them. Ask them any questions you may have.
Chapter 13

Learning More on Your Own

**Your school or public library**
Ask the librarian to help you find the information or support that you’re looking for in books, magazines, videos, or on the Internet.

**The Internet**
Use an Internet search engine and type in general words like “sibling” and “cancer” together to get started. Keep in mind that the Internet has a lot of good information. It also has a lot of poor information and false promises, so you may want to check with your parent or another trusted adult about what you find.

**Your sibling’s hospital or clinic**
Visit the patient education office at your sibling’s hospital, if there is one. Or, ask if you can go with your brother or sister during their visit to the doctor to learn more.
Help Is a Phone Call or Web Site Away

Here are some places to contact for help. You can call them or visit their Web site for more information.

**National Cancer Institute (NCI)**
**Cancer Information Service (CIS)**
1-800-4-CANCER (1-800-422-6237)
www.cancer.gov

NCI offers accurate, up-to-date information on cancer for you and your family. Call the CIS to talk to an information specialist who can answer questions you or someone in your family might have. Or go to LiveHelp on NCI’s Website to chat online with an information specialist. NCI can also help connect you with a support organization in your area. NCI offers many materials in both English and Spanish.

**American Camp Association**
1-800-428-2267
www.acacamps.org

The American Camp Association can help you find camps that are specifically for kids who have a brother or sister with cancer.

**American Cancer Society (ACS)**
1-800-ACS-2345 (1-800-227-2345)
www.cancer.org

ACS is a nationwide, community-based voluntary health organization. ACS provides information, programs and services, as well as events that can help you and a family member with cancer, through its many local offices and online services.

**American Childhood Cancer Organization**
1-855-858-2226 (toll free)
www.acco.org

The American Childhood Cancer Organization provides support, education and advocacy for children and adolescents with cancer, survivors of childhood/adolescent cancer, their families and the professionals who care for them.
Cancer Support Community (CSC)
1-888-793-9355 (toll free)
www.cancersupportcommunity.org
The Cancer Support Community (CSC) was formed by the merger of Gilda’s Club Worldwide and The Wellness Community. CSC is an international non-profit organization that has a network of personalized services and education for all people affected by cancer. Its free programs include support groups, counseling, education, and healthy lifestyle initiatives. These support services are available online and through local affiliates.

CancerCare
1-800-813-HOPE (1-800-813-4673)
www.cancercare.org
CancerCare offers free information and support by telephone and online to anyone affected by cancer. Visit their online support group for teens who have a family member with cancer.

Make-A-Wish Foundation
1-800-722-WISH (1-800-722-9474)
www.wish.org
Make-A-Wish grants wishes to kids who have life-threatening medical conditions. Your parents, your brother or sister with cancer, or their doctor can call Make-A-Wish to see whether your brother or sister can qualify.

SuperSibs!
1-866-444-SIBS (1-866-444-7427)
www.supersibs.org
SuperSibs! is a national non-profit organization that provides free services to brothers and sisters of children with cancer. SuperSibs! helps children and teens redefine the “cancer sibling” experience by providing them with ongoing recognition and support.
# Appendix

## Chart A: Monitoring Tests

<table>
<thead>
<tr>
<th>TEST</th>
<th>PURPOSE</th>
</tr>
</thead>
<tbody>
<tr>
<td>Biopsy</td>
<td>Used to find out whether a tumor or abnormality is cancer. Benign means it is not cancer. Malignant means that it is cancer.</td>
</tr>
<tr>
<td>Blood test</td>
<td>Checks the blood to see whether the balance of the cells and chemicals is normal</td>
</tr>
<tr>
<td>Bone marrow aspiration</td>
<td>Collects a small sample of cells from inside a bone to be examined under a microscope</td>
</tr>
<tr>
<td>CAT scan or CT scan (CT scan)</td>
<td>Uses x-rays and a computer to produce three-dimensional (3-D) images of the inside of the body</td>
</tr>
<tr>
<td>MRI (Magnetic resonance imaging)</td>
<td>Uses radio and magnetic waves to make images of organs and other tissues inside the body</td>
</tr>
<tr>
<td>PET scan (PET scan) (PET scan)</td>
<td>Uses computerized pictures of areas inside the body to find cancer cells</td>
</tr>
<tr>
<td>Spinal tap (Lumbar puncture)</td>
<td>Collects a sample of the fluid inside the spine to be examined under a microscope</td>
</tr>
<tr>
<td>Ultrasound (Ultrasonography)</td>
<td>Uses high-frequency sound waves to make images of internal organs and other tissues inside the body</td>
</tr>
<tr>
<td>X-ray</td>
<td>Takes a picture of the inside of the body using high-energy waves</td>
</tr>
</tbody>
</table>
## PROCEDURE (What Happens)

A doctor removes a sample from a person using one of two ways: with a long needle (needle biopsy) or by making a small cut (surgical biopsy).

A nurse or technician inserts a needle into a vein, usually in the arm. Then he or she draws blood.

A needle is used to remove a small sample of tissue from a bone (usually the hip bone).

The patient lies flat on a table, which moves through a large tube while a series of x-rays is taken.

The patient lies flat on a table, which moves through a large tube while an MRI machine scans the body for several minutes.

The patient gets an injection and then a machine takes computerized pictures of areas inside the body.

A needle is used to remove fluid from the spine in the lower back.

A technician moves a small handheld device over an area on the patient’s body. An image appears on the computer screen.

The patient is placed in front of the x-ray machine or lies on a table.
<table>
<thead>
<tr>
<th>TEAM MEMBER</th>
<th>WHAT THEY DO</th>
</tr>
</thead>
<tbody>
<tr>
<td>Child life specialist</td>
<td>A trained person who works with children and their families to make the hospital and treatment experience less scary</td>
</tr>
<tr>
<td>Nurse</td>
<td>A health professional trained to care for people who are ill or disabled</td>
</tr>
<tr>
<td>Nutritionist/dietitian</td>
<td>A health professional with special training in nutrition who can help with dietary choices</td>
</tr>
<tr>
<td>Oncologist</td>
<td>A doctor who specializes in treating people with cancer. Some oncologists specialize in certain types of cancer or certain types of cancer treatment</td>
</tr>
<tr>
<td>Patient educator</td>
<td>Educates patients and families about illness</td>
</tr>
<tr>
<td>Pharmacist</td>
<td>Dispenses medicines for patients</td>
</tr>
<tr>
<td>Physical therapist</td>
<td>Teaches exercises and physical activities that help patients gain more muscle strength and movement</td>
</tr>
<tr>
<td>Psychiatrist</td>
<td>A doctor who treats mental health problems, including depression, with medicine and talk therapy</td>
</tr>
<tr>
<td>Psychologist</td>
<td>Talks with patients and their families about emotional and personal matters and helps them make decisions, but does not write prescriptions for medicines</td>
</tr>
<tr>
<td>Radiologist</td>
<td>A doctor who looks at x-rays and other images of the body</td>
</tr>
<tr>
<td>Religious or spiritual leader</td>
<td>Addresses the spiritual and emotional health of patients and their families. This can be a chaplain, minister, priest, rabbi, imam, or youth group leader</td>
</tr>
<tr>
<td>Social worker</td>
<td>Talks with people and their families about emotional or physical needs and helps them find support services</td>
</tr>
<tr>
<td>Surgeon</td>
<td>A doctor who removes or repairs a part of the body by operating on the patient</td>
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Glossary

What the Terms Mean

This list can help you learn some words that your parents or the doctors and nurses may use. Don’t be afraid to ask questions when you don’t understand what they are talking about. These people are there to help you, too.

**Benign:** Not cancer. Benign tumors do not spread to the tissues around them or to other parts of the body.

**Biological therapy:** Treatment to help the body’s immune system fight infections, cancer, and other diseases. It is also used to reduce certain side effects of cancer treatment. Other names include immunotherapy, biotherapy, or BRM (biological response modifier) therapy.

**Bone marrow:** The soft, sponge-like tissue in the center of most bones. It makes white blood cells, red blood cells, and platelets.

**Cancer:** A term for diseases in which abnormal cells divide without control. Cancer cells can invade nearby tissues and can spread through the bloodstream and lymphatic system to other parts of the body.

These are the main types of cancer:

- **Carcinoma** starts in the skin or in tissues that line or cover internal organs.

- **Leukemia** starts in blood-forming tissue such as the bone marrow. Large numbers of abnormal blood cells form and enter the bloodstream.
• **Lymphoma** and **multiple myeloma** begin in the cells of the immune system.

• **Sarcoma** starts in bone, cartilage, fat, muscle, blood vessels, or other connective or supportive tissue.

**Cell:** The individual unit that makes up all the tissues of the body. All living things are made up of cells.

**Chemotherapy** or **chemo:** Treatment with medicines that kill cancer cells. Chemo is most often given intravenously (through a blood vessel). Some chemo can also be given by mouth.

**Clinical trial:** A type of research study that tests how well new medical approaches work in people. These studies test new methods of screening, prevention, diagnosis, or treatment of a disease.

**Depression:** A mental condition marked by ongoing feelings of sadness, despair, loss of energy, and difficulty dealing with normal daily life. Other symptoms of depression include feelings of worthlessness and hopelessness, loss of pleasure in activities, changes in eating or sleeping habits, and thoughts of death or suicide. Depression can affect anyone, and can be successfully treated.

**Diagnosis:** Identifying a disease by its signs and symptoms.

**Donor:** A person whose stem cells match with those of the person with cancer. Not everyone is a match. A patient’s brother or sister is more likely to match than someone who is not related.

**Hormone:** A chemical made by glands in your body. Hormones move in the bloodstream. They control the actions of certain cells or organs.
**Hormone therapy:** Treatment that uses hormones to slow or stop the growth of certain cancers such as prostate and breast cancer.

**Immune system:** Organs and cells that defend the body against infections and other diseases.

**Intravenous or IV:** Injected into a blood vessel.

**Leukemia:** Cancer that starts in blood-forming tissue such as the bone marrow and causes large numbers of blood cells to form and enter the bloodstream.

**Malignant:** Cancerous. Cells from a malignant tumor can enter and destroy nearby tissue and spread to other parts of the body.

**Metastasis:** The spread of cancer from one part of the body to another. A tumor formed by cells that have spread is called a metastatic tumor or a metastasis.

**Protocol:** A plan for treating cancer.

**Radiation therapy:** Treatment with high-energy radiation to kill cancer cells and shrink tumors. External radiation comes from a machine outside the body. Internal radiation comes from material put inside the patient near the cancer cells.

**Recurrence:** The return of cancer after a period when it seemed to be gone. The cancer may come back in the same place as the first time or in another place in the body. Also called recurrent cancer.

**Relapse:** The return of signs or symptoms of cancer after a period of improvement.
Remission: During remission, the signs and symptoms of cancer go away or are less than before. In partial remission, some, but not all, signs and symptoms of cancer have disappeared. In complete remission, all signs and symptoms of cancer have disappeared, although cancer may still be in the body.

Sibling: Another way of saying your brother or sister.

Side effects: Problems that can occur when cancer treatment harms healthy tissues or organs. Some common side effects of cancer treatment are feeling tired, pain, being sick to the stomach, vomiting, lower blood cell counts, hair loss, and mouth sores.

Stem cells: Cells from which other types of cells develop. For example, blood cells develop from blood-forming stem cells.

Stem cell transplantation: The use of healthy stem cells from the bone marrow or the bloodstream to replace cells that were destroyed by high doses of chemotherapy and/or radiation therapy. The transplanted stem cells may come from the patient or from donors. In many cases, the donors are family members. The patient gets the stem cells through an IV line.

Support group: A group of people with similar concerns who help each other by sharing experiences, knowledge, and information.

Surgery: An operation to remove or repair a part of the body.

Tissue: A group or layer of cells that work together to perform a specific function.

Transfusion: The infusion of certain blood cells or whole blood into the bloodstream. The blood may be donated from another person, or it may have been taken from the patient earlier and stored until needed.
Transplant: The replacement of tissue with tissue from the patient’s own body or from another person.

Tumor: A mass of tissue that forms when cells divide more than they should or do not die when they should. A tumor may be cancerous (malignant) or not cancerous (benign).

X-ray: A type of high-energy radiation. In low doses, x-rays are used to spot diseases by making pictures of the inside of the body. In high doses, x-rays are used to treat cancer.

Make a list of any terms that still aren’t clear to you. Talk to your parents, doctors, nurses, or other adult about your questions.
Acknowledgments

We would like to thank the many teens, scientists, and health professionals who assisted with the development and review of this publication.

To know the road ahead,
ask those coming back.

—Chinese proverb
While the diagnosis of a serious medical illness impacts the entire family, this can be an especially difficult time for siblings of pediatric patients. The Sibling Program at Dana-Farber/Boston Children’s Cancer and Blood Disorder’s Center provides support to these siblings and their families in the following ways:

**Just for Sibs Group**

We offer social and supportive groups for siblings of Dana-Farber/Boston Children’s patients. These sessions offer siblings a place to come together to connect, have fun, and make friends. While we aren’t able to meet in person right now, we still connect from home via zoom! During each group meeting we do a fun activity together as a way to hangout virtually and meet one another.

Currently, we offer two groups:

- Just for Sibs (siblings ages 5-10)
- Just for Sibs: Tweens and Teens (siblings ages 11-19)

**Books for Kids**

The Sibling Program provides reading materials including sibling journals and children’s books centered around adjusting to home life, family, and everything that goes along with having a sibling who has been diagnosed with a serious medical illness. These carefully selected resources are a wonderful way of providing information, encouraging children to ask questions and helping them to better cope with this new adjustment.

**General Information About Sibling Support and Available Resources**

Our staff are available to talk with you about your specific concerns related to sibling adjustment and connect you with additional resources to support these important members of your family.

**Join Us!**

To learn more about the Sibling Program or access any of the above supports, please fill out our registration form online. To access the form you can either:

Visit:  
https://redcap.link/JustForSibs

Or, scan the QR code on the right with your smartphone or device:
Sibling Voices Video

Dana-Farber’s Sibling Program provides support to siblings and their families. Through high-level care and ongoing research, our unique program is committed to further exploring the impact of a cancer diagnosis on siblings and creating a better experience for all involved throughout the cancer journey.

The video, Sibling Voices, was created by and for siblings who have a brother or sister with cancer. Please visit the link below to watch the video and hear more about the experience of siblings.

www.dana-farber.org/sibling-program

Also available on YouTube:
https://www.youtube.com/watch?v=c4mqXYm0yfc
OR scan QR code
Dear Parents,

Many people have heard the story of our daughter Alexandra “Alex” Scott who was only 4 when she held her first lemonade stand to raise money to find cures for kids, like her, with cancer. Fewer people know that Alex is one of four kids in our family. Although Alex was the one in treatment, her three brothers—Patrick, Eddie, and Joey—also experienced the impact of being part of a family affected by childhood cancer. We know that it has not always been easy for them dealing with the uncertainty, fear, and worry that comes along with a sibling’s cancer diagnosis, but their experience has also shaped them into the young men we are so proud of today. As we continue Alex’s legacy through Alex’s Lemonade Stand Foundation, Patrick, Eddie, and Joey are strong supporters and have been with us every step of the way.

Having grown up with siblings ourselves, we know the integral role they play in our lives, whether in good times or difficult times. There is nothing quite like the sibling bond, and the unique support and sense of normalcy that a brother or sister can give to a child in treatment. We are honored to be able to give siblings the support that they too need through SuperSibs!

Best regards,

Liz and Jay Scott

Parents of Patrick, Alex, Eddie, and Joey
"When our younger daughter was fighting cancer, it was hard on her and for us, but in the midst of this fight our older daughter faced her own lonely battle. We had to try extra hard so she didn’t feel less loved since we spent so much time at the hospital without her."

-Dash W.

"Over time, the impact of the focus on Payton played a role in her sister Jordyn’s personality. She tried harder to be noticed by us. She even wanted a scar like her sister and did her best to gain attention at every opportunity. As a result, Jordyn was and is both incredibly independent and at the same time incredibly dependent on our love and attention."

-Brian R.

"When his brother, Declan, was in treatment, SuperSibs sent Brendan his own gifts that I believe will continue to mean more and more to him as he grows older and works through the grief of losing his big brother to cancer."

-Megan R.

Comfort and Care Program

This program is specially designed for children ages 4-18 in the United States who have a sibling battling cancer currently or in the past. Over a two-year period, SuperSibs receive mailings that are age-appropriate, evidence-based, vetted by psychosocial support professionals, and designed to provide coping skills and encouragement.

Here’s what you and your SuperSib can expect:

- Up to 8 mailings per sibling each year
  - Holiday and seasonal postcards with activities
  - Two workbooks each year with fun games and exercises to validate feelings, develop healthy coping skills, provide encouragement, and recognize each SuperSib’s importance in their family
- Birthday and milestone cards
- Graduation plaque and card at the completion of the program
- Quarterly parent e-newsletters
- Online worksheets and archive of past mailings at SuperSibs.org

Each mailing is an opportunity to check in with your child. Ask what they received from SuperSibs or read the newsletter together. Talk about the activities, their feelings, and remind them how important they are to you!
SuperSibs at School

For children, school isn’t just where they receive their education. It’s also the center of their social universe. After a diagnosis, the school community can provide much needed support and stability for siblings. Extra support for siblings in the classroom can decrease their feelings of isolation, guilt, fear, or being misunderstood.

Some other ways teachers and school officials can be of help include:

• Siblings often face teasing or harassment because of what their hero is going through. It is important to be mindful of this even if the hero and SuperSib are not in the same school.
• School routine should remain the same as much as possible to ensure normalcy, but sometimes SuperSibs can benefit from decreased or modified academic assignments.
• Teachers and school administrators may pick up on SuperSibs’ needs that can be addressed at home, so keep in communication with them.

The ALSF’s School Guide: Supporting Families and Classmates Affected by Childhood Cancer is a free resource designed to help families and school professionals address the unique needs of children diagnosed with cancer and their siblings in the classroom. For more ways to support SuperSibs in the classroom, visit AlexsLemonade.org/School-Support. Available in print and for download.

Support Through Changes

ALSF will send special SuperSibs mailings to siblings when there are changes in treatment status. When there are updates like completion of treatment, remission, or even relapse, please let us know so we can stay in touch.

In the event their sibling passes away, we have specialized bereavement mailings for SuperSibs to enhance coping and acknowledge their grief. When we are notified of a patient’s death, we will also send an accompanying parent package. All updates can be made by calling (866) 333-1213 or emailing SuperSibs@AlexsLemonade.org.

Treatment Journal

ALSF’s Treatment Journal is a hand-held organizer designed to help keep track of appointments, labs, medications, nutrition, and many other details that come with managing a treatment schedule. To order your free copy, visit AlexsLemonade.org/Treatment-Journal. The organizer is also available in Spanish translation.

“I was worried about Dylan more than anything and how he was going to cope with this. I saw that ALSF has the SuperSib program and I really wanted to find something that would help him. As soon as we got out of the hospital I looked it up and got him enrolled in SuperSibs. It's helped him feel special and continue to provide amazing support and encouragement for Ryan.”

- Jennifer E.
Share, Connect, Inspire

An important part of coping with any life-changing experience is finding the support and strength to keep moving forward. ALSF’s Parent to Parent Network provides a great source of support by connecting caregivers who have had similar experiences. To learn more, please visit AlexsLemonade.org/Parent-Parent-Network.

Reading other’s stories and sharing your own can be therapeutic, as well as provide encouragement and inspiration. Visit AlexsLemonade.org/Stories.

Another way to share your experience is by attending events or speaking in the community to raise awareness about childhood cancer and its impact on a family. SuperSib Ambassadors pick their own level of involvement as well as which events to attend. More information at SuperSibs.org.

Camps for Childhood Cancer Families

Going to camp can be a memorable childhood experience, but for SuperSibs it can have a deeper meaning. Specialized camps can provide a common ground for sharing and coping among peers.

Visit SuperSibs.org for a list of camps across the country that have specific programming for siblings and for the rest of the family.

KEEP IN TOUCH!

To change your address, update family information, suspend SuperSibs mailings, or get in touch for any other reason, contact us at SuperSibs@AlexsLemonade.org or (866) 333-1213.
Tips for Parents: How to Talk to Siblings About Cancer

Though it can be intimidating to think about explaining cancer to your other children, it’s essential for them to receive honest, age-appropriate information. Without the facts, children often invent worst-case scenarios in their imaginations. Open, on-going conversations will help reduce unnecessary stress, guilt, and anxiety and build trust.

Your hospital’s pediatric oncology social worker, psychologist, child life specialist or nurse may have more suggestions and resources to guide you.

For Young Children (2-5)

Keep explanations simple. Here are some suggestions:

• Leukemia: “Sammy’s blood is sick. The doctors are going to give him special medicine to help his blood get better. Sometimes he will take it at the hospital and sometimes at home. The doctors are going to do everything they can to make his blood get better.”

• Solid tumor: “Stephanie has a bump on the inside of her head. The doctors want to make that bump go away, so they might try to take it out, or they might give her some special medicine to make it shrink.”

• Emphasize that they cannot catch cancer or cause it.

• Prepare them for physical changes like hair loss, bruising, and weight loss or gain.

For School Age Children (6-10)

Focus on giving information and asking questions to start a conversation. Here are some suggestions:

• Leukemia: “Sammy has cancer. Have you heard that word before? There are different kinds, and Sammy’s kind is called leukemia. That means that the cancer is in his blood. The doctors are going to give Sammy a strong medicine called chemotherapy. It’s called ‘chemo’ for short. The chemo will help make the leukemia go away.” Emphasize that doctors and nurses are going to do everything they can to make the leukemia go away.

• Solid tumor: “Sometimes the cells inside the body start to do strange things and the doctors don’t know why. The cells might start to be in a weird shape, or they might clump together into tumors. The doctors found one in Stephanie’s brain. The tumor was pushing on the part of her brain that help helps her walk and run and that’s why she was having trouble with her balance. The doctors don’t want the tumor to stay in her brain, so they are going to try to take it out with surgery. She will get medicine to help her sleep and not feel anything.”

• This age group may think cancer is contagious, like a cold, so making the distinction is important.

• It’s appropriate to prepare this age group for physical and emotional changes.

For Tweens and Teens (11-18)

Start with the basics and then elaborate, depending on how much information they want to hear. Every child will want different amounts of information, and some may want to read about it themselves.

Suggested questions for conversation:

• What do you know about cancer?
• Do you think you can catch cancer? (No, it’s not contagious.)
• Do you think cancer is caused by something someone did? (It’s not!)
• What do you want/need from us, your parents?
• What do you want/need from your friends?
• What do you want/need from school?
• How do you know that you are loved?
How to Help Your Child During Their Sibling’s Cancer Treatment

Siblings tell us the one thing they crave most is more time with their parents. We know how hard that can be, so remember that even brief, special moments can make a difference! Here are 10 ways to support your SuperSib:

1. Keep your SuperSib informed. This fosters a bond of trust that promotes healthier adjustment to the changes occurring within the family.
2. Have family and friends ask you (or a designated point person) for medical updates rather than asking your SuperSib.
3. Encourage medical professionals, friends, and neighbors to greet and introduce siblings by their own names (not as “patient’s brother or sister”).
4. If siblings are unable to visit the hospital, connect through video chat or send photos through text messages.
5. Remind your kids that it is OK to laugh and have fun, even while a sibling is undergoing cancer treatments.
6. Try to set aside brief, special times alone with your SuperSib to take a walk, get ice cream, or read a book together.
7. Connect your SuperSib with other siblings. Your social worker may be able to help connect you to other families, support groups, and community resources.
8. Older children often fall into a “third-parent” role during treatment. Avoid overloading your SuperSib with too many responsibilities, and instead call on family, friends, and community members.
9. Ask your children, one-on-one, how they are doing. Then, just listen. They have a life outside of cancer with their own hopes, dreams, disappointments, and successes.
10. April 10th is National Sibling Day. Use this day to celebrate your SuperSib!

Connect with Us Today!
facebook.com/alexslemonade twitter.com/alexslemonade

About SuperSibs Powered by ALSF
Melanie Goldish founded SuperSibs in 2002 after noticing firsthand the impact of childhood cancer on siblings and recognizing the importance of giving them support and compassion too. Later, in 2014, SuperSibs became a part of Alex’s Lemonade Stand Foundation (ALSF), a national nonprofit whose mission is to find cures for childhood cancer through funding innovative medical research and to support families throughout their journey.

About Alex’s Lemonade Stand Foundation
Alex’s Lemonade Stand Foundation (ALSF) emerged from the front yard lemonade stand of cancer patient Alexandra “Alex” Scott (1996-2004). In 2000, 4-year-old Alex announced that she wanted to hold a lemonade stand to raise money to help find a cure for all children with cancer. Since Alex held that first stand, the Foundation bearing her name has evolved into a national fundraising movement, complete with thousands of supporters across the country carrying on her legacy of hope. To date, Alex’s Lemonade Stand Foundation, a registered 501(c)3 charity, has raised more than $150 million toward fulfilling Alex’s dream of finding a cure, funding over 800 pediatric cancer research projects nationally. In addition, ALSF provides support to families affected by childhood cancer through programs such as Travel For Care and SuperSibs. For more information on Alex’s Lemonade Stand Foundation, visit AlexsLemonade.org.
TIPS TO HELP YOUR CHILD

Siblings of a child with cancer may experience a range of emotions including fear, anger, jealousy, anxiety, sadness and hopelessness related to their sister or brother’s diagnosis. They are often faced with changes such as their sibling not being able to play with them as usual and their extracurricular activities getting reduced or eliminated due to parents’ time constraints and focus on the child with cancer’s medical care.

Here are some tips on understanding how your healthy children may feel after a sibling is diagnosed with cancer and some practical ways to support them:

**Talk it through.** Give your children accurate, age-appropriate information about their sibling’s diagnosis as soon as possible. Don’t be afraid to use the word cancer. Explain the treatment plan and how it will affect them. Remember that if you don’t talk to your kids about cancer, they may come up with their own explanations, which can be even more frightening than the facts. Some children believe something they did, such as get in a fight with their sibling, caused the cancer. Let them know that nothing they did or said can cause cancer.

**Answer questions as accurately as possible.** Keep the lines of communication open by answering questions honestly, taking into account your children’s age and prior experience with serious illness in the family. If you don’t know an answer to a question, it’s okay to say that you don’t know and will try to find out. To maintain an honest and trusting relationship, replace statements like “everything will be okay” with “we and the doctors are doing everything we can to help your sister/brother get better.”

**Try to maintain normalcy** whenever it is possible. Routine gives children a sense of security and helps them cope with stressful situations.

**Prepare your children.** Explain the treatment plan and prepare your children for physical changes their sibling may experience (for instance, hair loss, fatigue, or weight loss). Talking about appearance changes ahead of time will help reduce fear when these changes happen. Let your children know about changes to their routine in advance (for example, “Daddy will pick you up from school instead of Mommy for a while.”)
Reassure your children. Let your children know that their needs will continue to be taken care of. While your children know that you love them, they may be feeling vulnerable and need more reassurance than usual. Explain that their sister or brother needs a lot of attention right now but that does not mean you love your child with cancer more than you love them.

Acknowledge feelings. Your healthy children may feel guilty, frustrated, angry, sad or selfish for not just feeling happy they are healthy. Let your children know that you understand this is a hard time for them too and that all feelings are acceptable. Feelings are never wrong. If they want to talk about how they are feeling, hear them out. Some children won’t want to verbalize how they are feeling. You can be supportive in other ways by helping them find healthy outlets such as writing, music, art or physical activity.

Identify supports. Help your children identify people they can talk to such as family members, teachers, their school guidance counselor or members of your faith community for extra support. It may be helpful to ask one of these people to look out for your well child. Pick someone the child knows and trusts and ask them if they can be there to help out if the child needs someone when you are not available.

It’s a team effort. If your children express interest in being involved in their sibling’s care, find ways for them to help out. Giving them age-appropriate tasks such as bringing their sibling a cup of water or an extra blanket can help them feel important and needed. Older children may be able to help out with watching their sibling or helping set up for meals.

Make time to be with the well children. While family and friends are understandably focused on caring for the child with cancer, it’s important to spend time with your well children too. Having time alone with you, even in small amounts, will mean a lot and is a concrete way of conveying that they are special to you.

Support for your family. You and your children are not alone. To learn about support services such as counseling or support groups, speak to a hospital social worker or call 800-813-HOPE (4673) to speak with a CancerCare oncology social worker.

CancerCare® Can Help
Founded in 1944, CancerCare is the leading national organization providing free support services and information to help people manage the motional, practical and financial challenges of cancer. Our comprehensive services include counseling and support groups over the phone, online and in-person, educational workshops, publications and financial and co-payment assistance. All CancerCare services are provided by professional oncology social workers and world-leading cancer experts.

To learn more, visit www.cancercare.org or call 800-813-HOPE (4673). Facebook: facebook.com/cancercare Twitter: @cancercare
Helping Siblings of Children Diagnosed With Cancer

Siblings of children with cancer feel a lot of stress. Family routines change, and they may feel experience anger, sadness, anxiety, and guilt. They may worry about what is happening to their brother or sister, feel afraid they did something to cause their sibling’s cancer, or feel as if they are getting less attention from their parents. They can also find it hard to manage school responsibilities and social relationships when everything at home is changing. Parents can help siblings adjust by explaining what is happening, talking with them about their feelings, making space for their concerns and worries, and making sure siblings have routines in the “new normal.”

Helping siblings cope with the cancer diagnosis

When a brother or sister has cancer, it helps siblings cope if they have information about what is happening. The most important thing parents can do is to be honest and share what they know in ways that are right for each child's age and stage of development. General strategies that help children of all ages include:

- Arranging visits to the hospital to see their sick brother or sister and to meet the health care team.
- Talking with the health care team about specialists that provide support services for siblings.
- Explaining the diagnosis and treatment in words your child can understand.
- Encouraging siblings to share their feelings with parents or other trusted caregivers.
- Planning for daily contact with a parent or trusted adult who’s a consistent part of the child’s life.
- Sharing information about the family's cancer experience with schools or day care.
- Engaging friends and extended family members to help create routines, keeping caregivers consistent as much as possible.
- Monitoring for changes in behavior and asking the school or health care team for support if siblings are showing signs of distress.
- Reassuring siblings that their feelings are normal and important.
- Letting them know that they are just as loved and valued as the child who is sick.
- Making sure they know they did not do anything that caused their sister or brother's cancer and that it is not contagious.

Helping siblings cope based on their age and developmental stage

Children of different ages are able to understand different kinds of information. Here are suggestions to help siblings based on their age and stage of development. All siblings, regardless of their age, will benefit from having some time with their parents each week that is focused just on them. For more information about talking with children about cancer in a loved one or family member, see [Helping Children When a Family Member has Cancer](#).
Infants and very young children (birth to age 3)

- Keep your baby or child near you, if possible. Talk with your cancer care team about whether infants can stay overnight when their sibling is in the hospital.
- Use video, phone, and other means so your child can see and hear you in real time.
- Record lullabies, stories, and messages for when you can’t be at home.
- Remind toddlers often that mommy or daddy will be back soon.
- Cuddle and hug them a lot.
- Do not try toilet training or other major developmental tasks until new routines are in place.

Toddlers or pre-schoolers (ages 3 to 5)

- Give a simple explanation that brother or sister is sick and that the doctors are helping them.
- Keep caregivers informed about your family situation.
- Continue to set limits on behavior the same way you did before, this is part of their routine.
- Know that children this age may respond to stress by acting like they did when they were younger (having accidents even though they were toilet-trained, having tantrums as they did when they were 2 or 3).
- Have siblings nearby to make it easier to involve them (for example, use a local Ronald McDonald House during hospitalization or treatment).
- Give simple reasons for a parent's crying and sadness, by saying "I am crying because I am sad."
- Take time to tell them that they did nothing to cause their brother or sister's cancer.
- Talk with the child life expert or social worker at the hospital about ways to provide positive reinforcement for your child's newfound independence and supportive role in the family.

School-age children (ages 6 to 12)

- Take your child to an educational or support program or a camp for siblings if available.
- Answer all questions honestly, including, "Will he (or she) die?" Get help from the social worker and cancer care team, if needed. "
- Offer repeated reassurance that the sibling did not cause the cancer.
- Support having fun, despite brother or sister’s illness – make sure they don’t feel guilty about it.
- Suggest siblings write or phone, and send drawings, pictures, text messages, email, or voice messages to the patient.
- Offer reassurance that the family will be OK.
- Explain that the parents’ distress, sadness, or crying is OK.
- When possible, let the sibling help choose where to go after school and have a voice in who they prefer to care for them when a parent can’t be there.

Teens (ages 13 to 18)

- Arrange for the teen sibling to tour the clinic and ask questions of the cancer team if they wish.
- Find out if the cancer center has a special group for siblings.
- Discuss spiritual concerns related to diagnosis.
- When possible, let the sibling help choose where to go after school and have a voice in who they prefer to care for them when a parent can’t be there.
- Provide assurance that the family will be able to handle the crisis.
- Encourage teens to keep up their usual involvement in school and other activities.
- Ask your teen to help out at home, but don’t expect them to take on all the caregiving, housekeeping, and other difficult tasks that need to be managed. It is important that they focus on their school success and have the same levels of responsibility before their brother or sister was diagnosed. If more help is needed to manage as a family, talk to the cancer care team about available resources.
- Monitor closely for new or risky behaviors in response to stress, and ask for help from psychologists or social workers on the cancer care team if needed.

**Ask for help**

Like parents, patients and their siblings will find that with the help and support of those who love them they’ll be able to handle this cancer crisis. Cancer care teams can refer you to skilled experts to help your family as needed, offering teaching, counseling, support, information, and other resources to make the task easier. Don’t hesitate to ask for help.

**References**


Last Medical Review: September 18, 2017  |  Last Revised: October 12, 2017

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Information for patients and families dealing with childhood cancer and blood disorders

Compiled by:
Dana-Farber/Boston Children’s Cancer and Blood Disorders Center

HELPFUL WEBSITES FOR SIBLINGS OF PATIENTS

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<thead>
<tr>
<th>Website Name</th>
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<th>Description</th>
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<tr>
<td>Alex’s Lemonade Stand</td>
<td>alexslemonade.org</td>
<td>Super Sibs program is available through Alex’s Lemonade Stand. Must apply online 866-333-1213 <a href="mailto:supersibs@alexslemonade.org">supersibs@alexslemonade.org</a></td>
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<td>American Cancer Society</td>
<td>cancer.org</td>
<td>ACS has lots to offer including: Helping siblings cope based on their age and developmental stage, support groups, literature on a large variety of topics, summer camps for children with cancer, research and educational programs. Search for “siblings” 800-ACS-2345</td>
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<td>American Childhood Cancer Organization</td>
<td>acco.org</td>
<td>Free services include: an annual bibliography and resource guide, quarterly newsletter, and handbooks to help families of children with cancer. Search for “siblings” 855-858-2226</td>
</tr>
<tr>
<td>Be the Match</td>
<td>Bethematch.org</td>
<td>Support for siblings of transplant patients. The changes your family experience going through transplant and recovery can be stressful for everyone, including brothers and sisters. Watch for signs of stress and learn healthy ways to help them cope with recovery. 888-999-6743</td>
</tr>
<tr>
<td>Cancer.Net</td>
<td>cancer.net/blog</td>
<td>Blog: How to Help Healthy Children Cope When a Sibling Has Cancer. Also has links to other helpful resources from American Society of Clinical Oncology (ASCO)</td>
</tr>
<tr>
<td>Club NEGU</td>
<td>negu.org/join</td>
<td>Encourage every kid fighting cancer to Never Ever Give Up by CONNECTING with families, bringing AWARENESS to their stories, offering them a network of helpful RESOURCES and sending the entire family continual doses of ENCOURAGEMENT throughout their journey. 888-648-6348</td>
</tr>
<tr>
<td>Leukemia and Lymphoma Society</td>
<td>llis.org</td>
<td>Support group for sibling’s information Publication for siblings: Sibs &amp; Talk about Cancer. 508-810-1300</td>
</tr>
<tr>
<td>Massachusetts Sibling Support Network</td>
<td>massiblingsupport.org</td>
<td>Supports siblings by creating welcoming communities for siblings across the lifespan; improving the range and availability of sibling support services; and providing education about sibling-related issues. 617-807-0558</td>
</tr>
<tr>
<td>National Cancer Institute</td>
<td>cancer.gov</td>
<td>The NCI has many publications dealing with childhood cancer; one specifically for siblings is called When Your Brother or Sister Has Cancer. 800-4-CANCER</td>
</tr>
</tbody>
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DANA-FARBER/BOSTON CHILDRENS CANCER AND BLOOD DISORDERS CENTER
| **On Belay** | on-belay.org | On Belay is a program that works to support children and ensure that no one is alone when a family member is going through cancer treatment at any stage. **866-442-3529** |
| **Project Sunshine** | projectsunshine.org | Offers teleplay and activity kits to bring joy and play to pediatric patients and families |

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ALSF School Guide:
Supporting Families and Classmates Affected by Childhood Cancer
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Cancer Diagnosis In The Classroom

A childhood cancer diagnosis can be difficult for teachers, administrators and families to manage in a school setting. This guide provides a useful set of tools and resources to refer to in and out of the classroom. Alex’s Lemonade Stand Foundation would appreciate hearing about your classroom experiences. Please write to us: FamilyServices@AlexsLemonade.org.

“Recently when a student in my class, beloved by peers and administrators, was diagnosed with leukemia, we all experienced the fear and sadness along with her. We wanted to make sure that she could prioritize her health while also maintaining the tether to normal life that school represents.”

- Emilie, high school teacher
At age 4, Alexandra “Alex” Scott, a young cancer patient, announced that she wanted to hold a lemonade stand to raise money to help find a cure for all children with cancer. Through annual lemonade stands and support from the thousands of people inspired by her spirit and determination, she was able to raise $1 million before passing away at the age of 8 from cancer. Alex’s Lemonade Stand Foundation (ALSF) carries on her vision of curing childhood cancers and is one of the leading funders of pediatric cancer research in the U.S. today.

In addition, ALSF is committed to helping families and their communities cope with a childhood cancer diagnosis by providing programs and services, like this guidebook.

A childhood cancer diagnosis impacts every aspect of a family’s life and particularly their school environment. When there is a student diagnosed with cancer in the classroom, it is an opportunity for the community to come together in support of the family and each other.

At ALSF, we believe every child diagnosed with cancer is a hero and their siblings are SuperSibs. These terms are used throughout this guidebook.

Although this information is based on a childhood cancer diagnosis, it may be useful in addressing other critical illnesses as well. Thank you to the school administrators, families and healthcare professionals who collaborated with ALSF to develop this content and are quoted throughout this guide. Among them, the following themes and advice emerged:

- **Educate students in the classroom about childhood cancer to avoid fear, misunderstandings or isolating the student.**
- **Involve the student in the classroom as much as possible while they are out for treatment to keep a sense of normalcy with their schoolwork, classmates and upcoming events.**
- **Provide extra emotional support to siblings of children with cancer in the classroom.**
- **Create a supportive and encouraging classroom environment to avoid bullying and harassment.**

Thank you for all you do to educate and enrich the lives of all children, but especially for being a source of support at a difficult time. For more information, please visit AlexsLemonade.org. Please reach out with your questions, concerns and feedback by emailing FamilyServices@AlexsLemonade.org or calling 1-866-333-1213.

**Thank you,**
Family Services Team
Communication is Key

The line of communication between the Hero Family and the school is central to creating the best experience possible. This section will help with planning and preparing for conversations with the family, faculty and students.
Talking with a Hero Family

Families often express feeling disconnected and unsure of how to communicate with the people in their lives after a critical illness diagnosis. This is especially true for schools because of how many individuals and systems are in place.

Reaching out and initiating communication with the family can remove the burden from them. It opens a dialogue about the family’s wishes and thoughts on the changes they are experiencing as they relate to the classroom environment.

TIP: Maintaining the family’s privacy, trust and dignity should be at the forefront of any decision or discussion.

To ensure open communication and a smooth transition for the family:

- **Designate one person from the school staff to be the primary contact person.**
  This person will receive and provide updates, coordinate sending materials and other items as needed. The student’s teacher, counselor, psychologist, nurse or principal can serve as the point of contact.

- **Work with the family to complete necessary paperwork.** This may include health and educational plans.

- **Assess whether or not the family wants to share the hero’s diagnosis with the school community.**
  Some families may be hesitant to share information. However, there are many benefits to raising awareness within the classroom to best support the family.
  Other families may be eager to share details with the school community. Establish a healthy balance between sharing information with the class and maintaining focus in the classroom.

- **Share your ideas with the family for addressing the circumstances in the classroom.**
  Be respectful if the family chooses not to follow your suggestions.

- **If possible, talk through how schedules may impact SuperSibs.**
  Determine whether there are opportunities for the school community to mitigate that impact.

- **In collaboration with the family, develop an ongoing communication plan in order to:**
  - Remain updated on the hero’s treatment status
  - Include and accommodate the hero in the classroom as much as possible
  - Address issues or concerns regarding SuperSibs

Check with your school to see if there is a protocol in place.
Talking to Kids about Cancer

Educating students about the hero’s diagnosis can foster a supportive and encouraging environment in the classroom. Though it can be intimidating to think about explaining cancer to children, it is essential for them to receive honest, age-appropriate information. Children who are not given the facts will often invent worst-case scenarios. Talking about cancer in a way they understand will decrease the likelihood of misunderstandings, bullying and isolation.

The following suggestions may help.

Ages 2-5

- Children may have a basic understanding of illness and taking medicine to feel better.
- They may associate cancer with more familiar illnesses, like a cold or flu.
- Emphasize that no one can catch or cause cancer.
- Keep explanations about a hero’s diagnosis simple.

Examples:
- “His blood is sick. The doctors are going to give him medicine to help his blood get better. Sometimes he will miss school because he has to be in the hospital to get the medicine or he will stay home because he doesn’t feel good.”
- “She has a bump on the inside of her head. The doctors want to make that bump go away, so they might try to take it out. They might give her a special medicine to make it smaller.”

Ages 6-10

- They might think cancer is contagious and not understand the physical changes associated with treatment.
- Generally, they are ready for basic information about a cancer diagnosis and treatment.
  
  Introduce vocabulary they may already have heard such as cancer, tumor, chemotherapy, radiation, surgery, etc.
- Begin conversations with leading questions.
  “Have you heard about cancer before?”
  “Do you know what cancer is?”
  “What do you know about cancer?”

Examples:
- “There are different kinds of cancer and he has leukemia. That means that the cancer is in his blood. The doctors are going to give him strong medicine called chemotherapy or ‘chemo.’ The chemo will help the leukemia go away.”
- “The doctors found a tumor in her brain. The tumor was pushing on the part of her brain that helps her walk and run and that’s why she’s having trouble with her balance. The doctors are going to try to take it out with surgery. She’ll be in a special kind of sleep the whole time and won’t feel anything.”
Talking to Kids about Cancer (continued)

Ages 11-18

- Students understand complex cause and effect relationships, such as illness and side effects.

- They may already know someone in their family with cancer. Students may make generalizations based on previous experiences and knowledge.

- Start with the basics of the diagnosis. Some students may want a lot of information about their classmate; others may want to avoid talking about it. Emphasize that diagnoses and treatment are unique and outcomes will vary.

- They are likely to deny feelings of fear or worry. If they want information, they are likely to search on the internet, confide in their friends or use social media.

Examples:
- “As you may already know, there are many different types of cancer and ways to treat it. Childhood cancer is very different than adult cancer; can you think of reasons why?”

- “What do you know about this type of cancer and how it’s treated? What kinds of side effects from these treatments do you think may be possible?”

- “She will be in the hospital for the next few weeks to start treatment. We can imagine how hard this will be for her. Let’s talk about some ways we can show our support and keep in touch with her.”

Preparing Classmates for Potential Changes

A childhood cancer diagnosis can have many physical and emotional effects on members of the family. These changes are normal given the circumstances. It’s important to prepare students for changes they may see, including:

- Looking or acting different
- Less energy, more tired
- Missing school
- Not participating in activities the same way as before

Help the hero or SuperSib feel included and avoid focusing too much on these changes to help everyone adjust.

However, a diagnosis may also cause a range of emotions from other students, so it’s important to support them.

Here are a few ways:

- Acknowledge their feelings. It is okay to feel angry, sad or confused.

- Stress the importance to students of reaching out to adults such as their teacher, school counselor, school nurse or parents to express their emotions.

- Offer extra support and counseling to students who need it. Be sure their parents know of this offer too.

- Be aware of signs of withdrawal, acting out, change in behavior, loss of interest, not completing assignments, dramatic change in grades, regression, etc.
Questions and Answers

Your students may have many questions about the hero. Encourage questions so they are able to fully understand the situation and how best to support their classmate. Remind your students not to dwell on the topic so that they keep a balance of healthy thoughts and feelings.

Below are frequently asked questions by kids about cancer and suggestions for how to respond:

Q: Can I catch cancer?
A: No, it is not contagious.

Q: Why does your hair fall out?
A: The medicine they are taking, called chemotherapy, sometimes makes hair fall out.

Q: Can my friend still play?
A: It depends on how they feel. We can ask them when they return to school.

Q: How did they get sick?
A: Doctors do not know why some children get cancer.

Q: Will they die?
A: Doctors are doing everything they can to prevent that from happening.

Q: How can I be a good friend to them?
A: Support them! Be respectful of their privacy and their abilities. Be the good friend you’ve always been.

Q: What can I do?
A: Help them with assignments in class, share notes they missed, offer to carry books, ask them how you can help them today and be friendly.

Q: Can I talk with other friends about this?
A: Be mindful of respecting the hero’s privacy and do not gossip.

Q: Should we visit them in the hospital?
A: We need to check with the family to see if they are allowing visitors.

Q: Will they still participate in extra-curricular activities?
A: We can ask them. They might have to decrease their involvement this season/year while they are receiving treatment.

Q: Can they still go to school?
A: Depending on their treatment schedule and how they are feeling, they may have to miss some school.
Transitioning back to school

In addition to their education, children think of school as their social world. This section discusses ways to prepare the Hero Family and classmates for the return to school after a diagnosis.

“Mia couldn’t go to school because she was in active treatment. When her sister went back to school, Mia, who is quite the trickster, tried to sneak on the bus to go to school with her.”

– Melissa Bento, Mia’s mom
When children are out of the classroom for extended periods of time, they often feel isolated. Maintaining communication with the hero and SuperSib will help everyone stay connected and will create a smoother transition upon their return.

**TIPS:**

**Stay connected**

- Utilize technology in the classroom and for lessons. Skype or send videos and pictures.
- Keep student and family updated on school activities and events.
- Write letters or cards with support and encouragement to the hero and their SuperSibs.
- Involve parents in the classroom to support the family (i.e. providing meals/restaurant gift cards, carpool, homework delivery, sending items to the hero and sibling, etc.)
- Help cancer patients stay connected to their classmates: [MonkeyInMyChair.org](http://MonkeyInMyChair.org)

Each child receives a stuffed monkey that takes their place in school when they can’t be there.
Provide extra support or necessary accommodations in the classroom

- Allow for accommodations such as wearing hats, eating snacks or drinking water during class, taking breaks more often, restricted physical activities and academic pursuits.
- Work with the school nurse to ensure all daily medication and medical needs are addressed.
- Make a plan for emergency situations such as the hero getting ill in the classroom.

Encourage group work and other activities that the hero is excited for their return

Are they excited to...

- See friends?
  Assure the family that their classmates are looking forward to seeing them/welcoming them back.
- Participate in art class, music class and clubs?
  Remind the hero that adjustments and accommodations can be made if they are nervous about participating.
- Share their story?
  Ask them if/how they want to talk about their experience.

Suggest a small class conversation about their diagnosis and treatment to address questions, normalize visible changes and reduce stigma. Offer a teacher, nurse or other trusted school professional to co-present if the hero doesn’t want to do it themselves.

- Throw a welcome back party! Roll out the red carpet and celebrate the hero’s return to the classroom. Be sure the family is comfortable with this.

“As a certified school nurse, I find team teaching with the student with cancer to be an empowering way for the student to express their thoughts and feelings to their peers. The end result is enhanced understanding while negating bullying and harassment.”

- Lynn Owen, RN, BS, MPA
  Certified School Nurse
  Haddon Township, NJ School District
Addressing potential challenges of the hero and SuperSib’s return

Discuss potential challenges with the hero on the school bus

- Cancer treatments often causes nausea and the hero may be prone to motion sickness.
  - Discuss with bus driver to address unforeseen issues.
- Work with the bus driver to keep an eye out for potential bullying or harassment.
  - Ask the hero and SuperSib to think about friends they can sit with to feel safe and comfortable.

Confirm with the family that all school professionals will keep an eye out for potential bullying and/or harassment issues

- Bullying is most prevalent in areas that are less supervised.
  - To help prevent bullying:
    - Encourage the hero and SuperSib to speak up about any unwanted or threatening behavior.
    - Pair the hero up with a “buddy” to be their seat neighbor.

When the hero and SuperSib return to school:

- Create a sense of normalcy in the classroom.
  - Stick to routines as much as possible, but be flexible to create new ones as needed.
- Some heroes and SuperSibs, especially in older age groups, become hyperfocused on their schoolwork and staying connected to their activities.
  - This is a way of creating their own sense of normalcy when everything around them has changed.
  - Let them set their pace and stay in touch.

If a hero displays any educational difficulties, communicate with the parents so they can discuss it with their doctor

- Make necessary accommodations and recommendations for learning support.
  - This may or may not require a formal individualized educational program (IEP) or 504 plan.
  - Be aware that these issues may become permanent and need long-term planning.

Ensure a smooth transition for aspects that might make the hero and SuperSib anxious such as...

- What will their friends think?
  - Reassure them that friends and classmates are excited for their return to school.
  - Share what information has been conveyed to classmates to clear up any misconceptions that the return is a surprise.
- What will be the physical toll of attending school and doing homework?
  - Talk through ways to reduce stress and fatigue.
  - Remind them that homework and schedules can be modified.
  - Make a plan for taking breaks when needed (i.e. visiting the nurse’s office, stepping into the hallway, etc.)
Heroes are at higher risk for educational challenges.

Cancer treatments may affect memory, learning abilities and fine motor skills temporarily or permanently. Some areas include:

- Handwriting
- Spelling
- Reading
- Vocabulary
- Math
- Concentration
- Attention span
- Ability to complete tasks on time
- Memory
- Multi-step processing
- Planning
- Organization
- Problem-solving
- Social skills

Meet Sullivan

“Until November 2016, Sullivan’s health was fine. Then, he was diagnosed with brain and spine cancer. As a parent, it was one of my biggest fears come true. Sullivan bravely underwent multiple surgeries to partially remove the main tumor and release the pressure on his brain. Sullivan’s tumor removal surgery resulted in Posterior Fossa Syndrome which affected his vision, speech and ability to walk.

Today, Sullivan continues the long process of rehabilitation and adaptation to his new life as a cancer survivor. He has made miraculous strides in physical therapy, but the effects of the treatments are extremely damaging.

Sullivan has worked back up to being in school full time and has caught up, but due to the devastating effects of radiation and chemo, some accommodations have to be made to help him deal with challenges that he never struggled with before. Sullivan’s short-term memory and mental focus are not what they were before cancer, but we had no choice. To save Sullivan’s life, those treatments with all those side effects were necessary.”

-Jen Butler, Sullivan’s mom
Prepare classmates for the return of the hero and SuperSib

The hero’s physical appearance may be different

- Weight loss or gain
- Missing hair, eyelashes or eyebrows
- Changes in skin tone, scars and bruising

Keep the topic honest, but general: “Our friend is coming back to class and you may notice some changes. Her hair has fallen out because of the medicine. It is in the process of growing back, so she might wear a hat for a while. Let’s make our friend feel welcome and comfortable.”

What else might be different?

- As mentioned in the “Communication is Key” section, in addition to possible physical changes, they may have less energy and may not act the same as before the diagnosis. They may not enjoy activities in the same way.

SuperSibs may also appear different as they are working through the stress and grief of the diagnosis and changes in their family.

- The hero may need accommodations that are exceptions to school rules that the rest of the class still needs to follow (ie. wearing a hat in school, eating snacks during class, taking breaks, etc.).

Set some ground rules if the hero gets sick in the classroom:

- Classmates will feel a sense of responsibility to help protect their friend.
- Help the hero feel less embarrassed about getting sick in front of classmates by responding calmly and deflecting the class’ attention.

Encourage students to focus on the present rather than what the hero missed while they were out of school.

Provide examples of positive things to say:

- “Is there anything I can do to help you with today’s assignment?”
- “Good to see you today!”
- Brainstorm more ideas with your class.

How can the class support the hero?

- Help the hero acclimate by welcoming them back and sticking to typical classroom routines. Don’t single the hero out.
- Offer—but don’t insist—to help with classroom activities.
- Be a good friend by listening and being kind.
- Show empathy instead of sympathy. Try to think, “How would I want to be treated?”
Encourage students to resist asking SuperSibs lots of questions about the hero

- They may not know the answers depending on how much is being shared with them at home.
- Instead, say “We are sorry about your brother or sister and hope they get well soon. How are you doing?” or “Would you like to talk about anything? I’m here for you.”
- With all the attention the hero is receiving, SuperSibs often feel left out and uncomfortable answering questions about the hero.
- Direct questions to designated school point of contact.

As a group, discuss what is appropriate to say or ask

- Ask the group ahead of time what kinds of questions they have.
- It is okay for students to ask the hero questions about their treatment and diagnosis as long as they are respectful and understanding if the hero is not comfortable answering or talking about it.

Remind students to respect the hero and SuperSib’s privacy

- Don’t repeat things that are shared by the hero or SuperSibs to other students.
- Stop or prevent gossip when they hear it; gossip is usually untrue and can be a form of bullying.

Steer students away from asking questions about death

Other examples of appropriate and encouraging phrases:

- “We missed you!”
- “Good to have you back!”
- “It’s nice to see you!”
- “How are you feeling today?”
- “Can you tell me what happened?”
- “What does that medicine do?”

Hero Julian with SuperSib brother Brayden
Prevent Bullying and Harassment

Childhood cancer comes with many changes for both heroes and SuperSibs. Sometimes, those changes can lead to bullying. This section discusses ways to prevent bullying in your community and make sure everyone feels supported.
Bullying often occurs in response to unfamiliar and sudden changes. Here are some ways to address and prevent it in your school community:

- Check in with the parents and, if possible, the hero about how they would like to address their change in appearance.
- Have a discussion with students about these changes before or when the hero comes back to school.
  Some heroes like to be the one to talk about these changes.
  - This can be done in collaboration with a school professional to help guide the discussion.
  - This can foster a sense of normalcy and acceptance.
- Some schools opt to have an event to show solidarity with the hero, which prevents ostracism (hair-cutting or head shaving, hat day, scarf day, etc.)
  It’s best to discuss this in advance with the family.
- Bullying is most prevalent in areas that are less supervised.
  Make it a priority across the school administration to be extra observant of the students.
  Address potentially harmful behavior quickly and diligently.
- Be sure to include the hero and sibling’s bus driver(s) in these conversations; bullying often takes place outside of the classroom.
- Create an environment of respect and comfort for the hero and SuperSib, but avoid singling them out.
  While they need extra support from their classmates during this time, it can be embarrassing.
  The extra attention can create an imbalance among classmates that fosters resentment, which can lead to harassment.
  Provide realistic examples of positive ways to engage with the hero and SuperSibs.
  - “Is there anything I can do to help you with today’s assignment?” “Good to see you today!”
  - Talk about anything other than cancer (ex., music, movies, video games, etc.)

Siblings often face teasing or harassment because of what their hero is going through. Be mindful to address this even if the hero and SuperSibs are not in the same school.
Supporting Siblings

Siblings of children with cancer can go through significant psychological stress while their sibling is fighting cancer. This section discusses ways to ensure they feel supported by the school community and continue open communication with their parents.

“Something as simple as making the classroom more comfortable can make all the difference. One of my teachers did everything he could to surround me with positive energy and people. When working with partners, he made sure I was paired with one of my close friends. When you come in and feel totally separated from everyone and feel as if people do not understand you, it is nice to be physically close to someone who makes you feel loved.”

-CARA, SUPERSIB – sister, Caitlin, was diagnosed when Cara was in 8th grade
Siblings of a childhood cancer hero typically experience distress due to the fear and uncertainty of their sibling’s diagnosis. At home, the focus is mostly on the hero, and SuperSibs may not want to share their feelings for fear of being a burden. Providing a safe, supportive environment at school may decrease their feelings of isolation, guilt, fear or being misunderstood.

**TIP:** You can also encourage the Hero Family to sign up for the SuperSibs Comfort and Care program. This free mailing program is designed to provide age-appropriate, evidence-based activities and worksheets to help siblings learn coping skills, receive encouragement and feel empowered during their family’s battle against childhood cancer. Parents can find more information and register their child at SuperSibs.org.

### CLASSROOM SUPPORT

- Provide as much positive feedback as possible.
- Understand they may need decreased or modified academic demands. Some SuperSibs want more work or activities to direct their focus away from what is happening at home. Offer suggestions based on your observations.
- Younger SuperSibs may benefit from a reward system initially after diagnosis.
- Maintain classroom routines as much as possible.
- Resist the temptation to exempt SuperSibs from important school/classroom rules. Flexibility is important, but so is the safety and well-being of the entire school community.
- Specifically include and recognize SuperSibs when sending letters, goodies or resources to the hero and family.

### DISCIPLINARY ISSUES

- View irritability as sadness rather than confrontation.

Communicate with other staff about how to address behavioral concerns as part of a broader intervention.

If behavior absolutely requires disciplinary action, be sure to include the parents in this discussion.

- *Follow up with the SuperSib to see if there is any extra support you can give them.*

Addressing problematic behaviors early on may decrease issues in the classroom later.

### COMMUNICATE WITH PARENTS AND/OR GUARDIANS

- Always check with the family on how comfortable they are sharing information with classmates and community.
- The more they understand what is going on at school, the more they can help the child at home.
- Sharing challenges or problems in the classroom with the family may seem like an added burden, but it’s essential to avoid larger, long-term problems.
- Emphasize areas where the SuperSib is doing well and prevailing.
  - This provides comfort and encouragement to parents at a time when it feels like everything is upside down.
EMOTIONAL SUPPORT

• Let SuperSibs know you care about their well being and provide opportunities for them to confide in you or someone else.

  Gently encourage sharing feelings and concerns with teachers, school counselors, school nurses, school psychologists or parents.

  Use caution to not appear as though you are pressuring the SuperSib to share more than they are comfortable sharing.

• Focus on how the SuperSib is coping.

  Try to not ask only about how the hero is doing. They may not be comfortable sharing personal information or stories and could feel pressure to lie and say something positive.

• Talk about things specific to the SuperSib.

  Talking about things other than cancer can be extremely helpful. Ask them about their extra-curricular activities, other classes, hobbies, etc.

• Validate their feelings.

  SuperSibs may not want to seem like a burden since they are not the ones who are sick. Validate that it is okay for them to feel upset, scared or angry.

• Promote peer support and connection.

  Encourage classmates to provide a comforting and supportive environment for the SuperSib. Peer support is especially important for teenage SuperSibs.

• Recognize common reactions and emotions.

  Stress, grief, confusion, anger, sadness, decline in academic performance, difficulty concentrating, and acting out in class are all signs that the SuperSib is struggling and needs support.

  SuperSibs who appear to be overachievers need support too. Some SuperSibs may start to excel and participate more in the classroom.

Be sure to check in regularly with SuperSibs and communicate with their parents. This ensures everyone can support the SuperSib in coping and processing their emotions.
Bereavement and Grief

A loss in the school community is devastating. It has a deep impact on students and the classroom. You know your classroom best. Work with your team to come up with a plan to share the news with the community and support students and staff.
Talking to students about death

PLAN IT OUT

Work with the Hero Family, your school team and school district officials (especially mental health professionals) to determine the best way to tell students. Aspects to consider:

- What does the family want the classroom and school to know?
  Respect the family’s wishes, but offer your knowledge, experience and best practices as guidance.
  Some families would rather not make an announcement, so you may need to come up with a plan on how to address questions from the school community.
  Be prepared to offer suggestions of how the news could be shared.

- Who will tell the students?
  The teacher is not the only option; the school counselor, the school nurse, or another trusted official can be included in the conversation.

- Should students be told in small groups or the whole classroom at once?
  Depending on the atmosphere of the classroom and the closeness of the students, it may be best to tell specific students individually, like their closest friends or students who have shown a lot of emotion regarding the diagnosis.

- How will the news be shared with the rest of the community?
  Your school district may already have protocol for sharing this type of news. Consider whether adjustments need to be made based on the nuances of the hero’s diagnosis and battle.
  Depending on your district’s protocol, consider informing the parents of the student body prior to sharing the news with students. This allows parents to debrief with their children and prepare for their child’s response.

“The life and legacy of Alex Scott left a lasting impact on everyone who knew Alex and on all the children and families yet to attend Penn Wynne Elementary School. First and foremost, Alex was our best teacher. We took our cues from her; Alex was a remarkable child, brave, smart and kind. We enjoyed every minute of the three years we had with her, and we learned to communicate openly and honestly about her illness. Equally important, we appreciated her parents, Liz and Jay Scott, for their wise counsel and courage.

No one is prepared for a devastating illness or the death of a child. What we learned was that we could rely on one another and that there were many resources available to us. Don’t be afraid to ask questions and access support. It’s there for you. It has been years, and Alex’s spirit is stronger than ever. The students, staff and families of Penn Wynne Elementary School carry on her determination to cure childhood cancer, and they do so, as Alex did, ‘one cup at a time.’”

- Gail, Alex’s Principal
  Penn Wynne Elementary School
Heroes are often integrated with the whole school. You may not realize the connections some students have with others in different classrooms or how they will be impacted by the loss.

Anticipate how the news will travel and how quickly. 
- If the news is not shared by the school administration, gossip may create a negative environment for SuperSibs and classmates who were closest to the hero.

Provide age-appropriate explanations, give concrete details and use words such as death and dying.

- Avoid vague phrases such as “a better place,” “sleeping,” “not with us,” “lost,” or “up in the sky” as they can be confusing for children.

Different age groups understand and react to death differently. Increasing their understanding of death will allow them to better cope with the loss and grieve their classmate.

PRESCHOOL AGE – may believe death is temporary, may view it as “sleeping”; begins to understand concepts of irreversibility.

- Common reactions: may have separation fears; may display regressive behaviors.

AGES 6-8 – understand death is not reversible.

- Common reactions: may internalize death, display physical reactions to emotion, exhibit regressive behaviors.

AGES 9-12 – understand death is not reversible.

- Common reactions: fixating on details, acting out, withdrawing or appearing indifferent so they don’t stand out to peers or feel vulnerable to emotion.

AGES 13-18 – adult-like understanding of death; likely to think about short and long-term effects of this death on themselves and family.

- Common reactions: asking detailed questions, withdrawing and pulling away from friendships, struggle with expressing feelings, difficulty focusing.

HOW TO HELP:
Encourage asking questions, sharing concerns, feelings or fears through ongoing communication.

Be aware that students may have different reactions and ways of coping.

Normalize the variety and complexities of emotions felt during a loss.

- Example: “It’s okay to feel sad when you think of missing them, but it is also okay to feel happy when you think of fun memories with them, too.”

Modeling appropriate and healthy reactions will encourage the students to express their emotions as well.

Provide a private space for students who need time alone to grieve. Refer students to school counselor, school social worker or school psychologist for extra support.
Classroom support during grief

BE PROACTIVE WITH SUPPORT FOR STUDENTS

- Don’t wait until there is need for emotional or extra academic support.
- Adjust or adapt assignments and lesson plans as needed.
- Identify school officials students can reach out to such as their teacher, school counselor, school social worker, school nurse or school psychologist.
- Grief will impact students in the classroom differently.
  
  Some students may be visibly distracted or have difficulty paying attention.
  
  Other students may appear to be resilient as they become more involved and active in the classroom. These students may or may not be processing or accepting their grief, which can cause more issues down the road.
  
  Encourage open communication and check-ins to assess how all students are coping.
- Update parents on how their child is reacting in the classroom so they can provide support at home.
- It may be helpful to process grief and stay positive by doing something productive and meaningful such as sending cards to the family or working on a memorial project.
- Keep classroom routines as consistent as possible.
- Take time for self-care and support for teachers and administrators. A loss in the school affects school professionals just as much as students.

“When a student in my classroom died unexpectedly, I knew that her classmates would be profoundly impacted. I was surprised, however, that some students were significantly impacted for prolonged periods. I could not have predicted this because, the students didn’t appear very close to the deceased student in the classroom. I found that it was important to watch for signs of grieving in all of the students, not just the ones who seemed closest to the deceased student.”

- Mary Jane, Special Education Teacher
Resources/Appendix

If you’re looking for more resources to share with students or add to your school community, the following will provide additional information for support during a childhood cancer diagnosis.

GENERAL RESOURCES

- Children’s Oncology Group School Support Guide

SUPER SIBS RESOURCES

- When Your Brother Or Sister Has Cancer: A Guide Book For Teens, National Cancer Institute
- Hi, My Name is Jack: A Book for the Healthy Siblings of Chronically Ill Children, by Christina Beall-Sullivan

GRIEF AND LOSS RESOURCES

Coalition to Support Grieving Students

- Video and Downloadable Grief Support Modules for School Personnel


- “Children & Loss: Teachers serve as a crucial emotional bridge for a child at times of loss. What do we need to know to help students cope?” Scholastic, by Bruce D. Perry MD

- “Death and Loss: Helping Children Manage Their Grief” Scholastic, by Bruce D. Perry MD, April 2006

- Children & Grief: Guidance & Support Resources

- “Grief in Schools,” Highmark Caring Place

- Finding Your Way Through Sudden Loss and Adversity: A Workbook by Hold The Door For Others, Inc.
Get Involved

SUPERFRIENDS
Anyone can be a SuperFriend Ambassador! If you or any students know a friend with cancer, their siblings or their parents, they can sign up to share their story and teach others how to be supportive during this difficult time.

HOST A LEMONADE STAND
Perfect for any time of year, this signature fundraising method lets students take a stand against childhood cancer! Mix, pour and find a cure in your classroom by hosting a lemonade stand. Hosting an Alex’s Lemonade Stand will help fund treatments and cures.

CHAMPION FOR KIDS WITH CANCER
Student-athletes of any age can sign up as a Champion and ask for one-time donations or pledges that multiply based on what statistic they track. From home runs to wins to baskets, no matter the stat, athletes of almost any sport have a chance to give back! Go to ALSFChampions.org.

ORGANIZE AN AWARENESS DAY
Host an awareness event like a hat day, pajama day or yellow day where students donate to dress up and raise awareness for childhood cancer! Students will love the chance to wear something different to school, and the school community will rally against childhood cancer together.

LEMON CLUB
Give high school students a chance to give back and raise awareness for childhood cancer in your community. Take a leadership role and organize a Lemon Club to help a great cause in the process.

Go to AlexsLemonade.org/Get-Involved to sign up today!
Acknowledgements

Special thank you to Dr. David Schonfeld, Professor of the Practice in the Suzanne Dworak-Peck School of Social Work and Pediatrics at the University of Southern California and Children’s Hospital Los Angeles and Director of the National Center for School Crisis and Bereavement. Thanks as well to the Siblings Program at the Dana-Farber/Boston Children’s Cancer Center and Blood Disorders Center for contributing their resources, knowledge and research to this topic.

For more information and resources visit AlexsLemonade.org or email the Family Services team at FamilyServices@AlexsLemonade.org.
Tips for Teachers: The Sibling Experience

Siblings who have a brother or sister being treated at Dana-Farber/Boston Children’s often experience challenges. While children may react differently, below are some reactions siblings may experience, along with some suggestions that may be helpful.

Possible Sibling Reactions to a Brother or Sister’s Illness While in School

- Complaints of not feeling well
- Withdrawal such as participating less or being less social
- Change in academic performance
- Periods of extreme productivity (over-achievement)
- Frequent absences or tardiness

Suggestions

School is often the place where a sibling can get a break from the concerns that they have. Sometimes, giving the sibling space, and not asking how the family or patient is coping, is most helpful. Check in with the student to see what is helpful to them during this time.

- Provide as much positive feedback as possible
- View irritability as sadness rather than confrontation
- Confirm the contact list of adult caregivers for sibling
- Encourage peer support
- Modify academic demands
- If you are an educator and have concerns about a sibling in your school, please contact the parent(s) or guardian(s).

Contact Us

For patient care assistance, please call the following phone numbers:

- Jimmy Fund Clinic (617) 632-3270
  Business Hours 8 a.m. to 5 p.m., Monday through Friday
- Page Operator (617) 632-3352
  Off hours: weekdays after 5 p.m., holidays, and weekends
  Page pediatric hematology/oncology fellow on call
- Life Threatening Emergencies dial 911

The information on this page is for patients who are receiving care at Dana-Farber/Boston Children’s Cancer and Blood Disorders Center. The information is not meant as a substitute for professional medical advice. Always speak with your health care provider with any questions you may have. For emergency medical care, call 911.
College Scholarships for Siblings

- **Northwestern Mutual**  
  https://learnmore.scholarsapply.org/nmsibling/
- **Ulman Foundation**  
  https://ulmanfoundation.org/scholarships/
- **The Izzy Foundation**  
  https://theizzyfoundation.org/scholarships/
- **John Foy and Associates**  
  https://www.johnfoy.com/about/scholarship/strong-arm-leukemia-scholarship/
- **Sofia's hope**  
  https://www.sofiashope.org/scholarships
- **Jackie Spellman Scholarship Foundation**  
  https://jackiespellmanbenefit.org/
- **Alex's Lemonade Stand Foundation SuperSibs!**  
  http://www.supersibs.org/
- **Children's Brain Tumor Foundation**  
  https://cbtf.org/scholarships/
- **Jeremy Cares**  
  https://www.jeremycares.org/copy-of-college-scholarships
- **Beat Cancer Today.org**  
  https://beatcancertoday.storenvy.com/scholarships

These are all separate opportunities with unique application processes and eligibility criteria.

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B.E.A.D.S. for Sibs is a program available to siblings of children being treated at Dana-Farber/Boston Children’s Cancer and Blood Disorders Center. Participants will receive a bead for significant events that are specific to the experience of having a sibling on treatment. Each bead and its meaning are shown on the bead image guide.

Participation is easy and fun! Sibs will receive a starter kit which will include a box to decorate and store beads, starter beads, a ringlet, and a journal.

To request beads at any time throughout sibling’s treatment, just fill out a B.E.A.D.S for Sibs order form and leave it in the mailboxes or with a staff member. Beads can be picked up either inpatient or outpatient at:

- 6N Resource Room @ Boston Children’s
- Blum Pediatric Resource Room in the Jimmy Fund Clinic

Thank You!

To the many organizations whose generosity makes this program possible at Dana-Farber/Boston Children’s Cancer and Blood Disorders Center.

*Disclaimer: By participating in B.E.A.D.S. for Sibs, the caregiver is assuming responsibility of safety related issues. Beads should only be handled with adult supervision. We recommend that parents be the ones to collect the beads for children under the age of three.
<table>
<thead>
<tr>
<th>Event/Experience</th>
<th>Bead Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Being Away From Parents/Caregivers</td>
<td>Multi-Colored Swirl Bead</td>
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<tr>
<td>Blood Disease/Hematology Awareness</td>
<td>Red Ribbon Bead</td>
</tr>
<tr>
<td>Bone Marrow Donor for Sibling</td>
<td>Bumpy Dots Large Hole Bead</td>
</tr>
<tr>
<td>Bone Marrow Testing</td>
<td>Animal Print Large Hole Bead</td>
</tr>
<tr>
<td>Bright Happy Bead</td>
<td>Glass Bee</td>
</tr>
<tr>
<td>Brother or Sister’s Diagnosis</td>
<td>Clear Large Hole Glass Bead</td>
</tr>
<tr>
<td>Camp</td>
<td>Flip Flop Bead</td>
</tr>
<tr>
<td>Celebrating a Birthday While Sib is on Treatment</td>
<td>Metal Birthday Cake Bead</td>
</tr>
<tr>
<td>Celebrating a Holiday While Sib is on Treatment</td>
<td>Marbled color beads</td>
</tr>
<tr>
<td>Childhood Cancer Awareness</td>
<td>Gold Ribbon</td>
</tr>
<tr>
<td>Changes in Schedule or Routine</td>
<td>Color Changing Round Tube Bead</td>
</tr>
<tr>
<td>End of Sibling’s Treatment</td>
<td>Pink Pig Bead</td>
</tr>
<tr>
<td>Expressing Feelings</td>
<td>Mixed Large Hole Beads</td>
</tr>
<tr>
<td>Family Members (Number of)</td>
<td>Gold Brass Bead</td>
</tr>
<tr>
<td>First Trip to the Resource Room/Playroom</td>
<td>Rainbow Large Hole Bead</td>
</tr>
<tr>
<td>Helping Out at Home</td>
<td>Large Silver Heart Bead</td>
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</tbody>
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<thead>
<tr>
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</thead>
<tbody>
<tr>
<td>Hospital or Clinic Visit with Sibling</td>
<td>Lampwork Cat Head</td>
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<tr>
<td>Joining Just for Sibs! Program</td>
<td>Rainbow Barrel Bead</td>
</tr>
<tr>
<td>Just Because</td>
<td>Green Ladybug Large Hole Bead</td>
</tr>
<tr>
<td>Making Something Special for Your Sib</td>
<td>Brown and Blue Glass Tube</td>
</tr>
<tr>
<td>Overnight Stays with Relatives or Friends</td>
<td>Metallic Large Hole Beads</td>
</tr>
<tr>
<td>Showing Bravery or Courageousness</td>
<td>Metal Bear Bead</td>
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<tr>
<td>Sibling Group</td>
<td>Bright Multicolored Round Bead</td>
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<tr>
<td>Sibling Relapse</td>
<td>Silver Puffed Heart Bead</td>
</tr>
<tr>
<td>Siblings Stem Cell Transplant Day</td>
<td>Large Hole Penguin Bead</td>
</tr>
<tr>
<td>Spending time with Someone Special</td>
<td>Assorted Colors with Sparkles</td>
</tr>
<tr>
<td>Starter Bead</td>
<td>Metal Dolphin Bead</td>
</tr>
<tr>
<td>Taking Good Care of Yourself</td>
<td>Round Wooden Bead</td>
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</table>

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Fill this out by making a check ✓ next to the bead you need. Someone will bring beads to the bedside (BCH) or can be picked up in the Resource Room.

<table>
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<tr>
<td>Spending Time With Someone Special</td>
</tr>
<tr>
<td>Taking Good Care Of Yourself</td>
</tr>
</tbody>
</table>

Name: ___________________________  Date: ____________

* Please leave this form in B.E.A.D.S. mailbox.*

Disclaimer: By participating in B.E.A.D.S., the caregiver is assuming responsibility of safety related issues. Beads should only be handled with adult supervision. We recommend that parents collect beads for children under the age of 3.

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SuperSibs, a program of Alex’s Lemonade Stand Foundation, is dedicated to comforting, encouraging and empowering siblings during their family’s battle against childhood cancer, so they can face the future with courage and hope.

I am so fortunate to be included in the long list of smiling children that are a part of the loving ALSF family. All I can really say is thank you so so much.
- Myles, 18, SuperSib

Alex’s Lemonade Stand Foundation (ALSF) is dedicated to finding cures for all types of childhood cancer by funding innovative medical research projects and helping families during their journey with the disease. The Foundation evolved out of the front-yard lemonade stands of Alexandra “Alex” Scott (1996-2004), a young childhood cancer patient who dreamed of helping other kids with cancer and their families raised $1 million before passing away at the age of 8.

Learn more at AlexsLemonade.org or SuperSibs.org
SuperSibs Programs:

- **Comfort and Care Services** are a series of age appropriate mailings over a 2-year period to siblings ages 4-18, who have a sibling diagnosed with childhood cancer and reside in the U.S.
- **Sib Spot** is an online resource which includes activities and words of support for siblings and is divided into age appropriate sections.
- **Sibling Ambassador Program** offers siblings of children with cancer an opportunity to share their stories and experiences.

Other ways to get involved:

- **Feature your SuperSib’s story on our website!**
  Read other sibling stories to help your SuperSib know they are not alone in their journey.

- **My Childhood Cancer**
  Share your voice and have your childhood cancer experience be counted. Register to join ALSF’s Childhood Cancer Database Project (MyChildhoodCancer.org), to help us better understand how childhood cancer affects families.

To access any of these services and to sign up a sibling for the Comfort & Care program, visit SuperSibs.org.

**Questions?** 📧 SuperSibs@AlexsLemonade.org or 📞 866-333-1213
INTERESTED IN CAMP?

Rustic camp for the entire family
Location: Brewster, MA
Age: Seriously ill children under age 18 & their families

Overnight camp for patient, sibling opportunities & family weekends
Location: Ashford, CT
Summer Camp: Seriously ill children age 7-15
Hero’s Journey: Seriously ill teens age 16-18
Family Weekends: Families with seriously ill children age 5-15

Camp for the entire family
Location: Casco, ME
Age: Child with cancer must be 18 or younger
Eligibility: Check website for details

Overnight camp for patients and siblings
Location: Colebrook, CT
Age: 5-17
Camper: Campers must have gone through or be currently in treatment for cancer
Sib Side Camp: Open to siblings of Camp Rising Sun campers, ages 8-15, separate activities

Overnight or day camp for patients, and survivors with sibling option
Location: Massachusetts
Day Camp: Cancer patients, survivors and siblings
ages 6-12
Overnight Camp: Cancer patients or survivors ages 7-17
Fall Sibling Retreat: Siblings ages 13-17

Click on camp logos and program names to access online applications.
Please ask Blum Pediatric Resource Room staff for additional information!
**KISS Form**
*Kids Information and Stat Sheet*

*For Parents to Complete and Leave with Sibling’s Temporary Caregiver*

My Child's Name: ________________________________________________________________________________

His/Her Nickname: _______________________________________________________________________________

Name of my child’s school: _________________________________________________________________________

Teacher’s Name: __________________________________________________________________________________

---

### Weekly Schedule/Activities:

<table>
<thead>
<tr>
<th>Monday</th>
<th>Tuesday</th>
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<th>Thursday</th>
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</tr>
</tbody>
</table>

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### Allergies:

Is your child allergic to any foods? Please list: __________________________________________________________

Is your child allergic to anything else? (animals, material, etc?) _____________________________________________

---

### Favorite Things:

**Foods:**

_____________________________________________________________________________________________________

**Ice Cream:**

_____________________________________________________________________________________________________

**TV Show:**

_____________________________________________________________________________________________________

**Activity:**

_____________________________________________________________________________________________________

**Book:**

_____________________________________________________________________________________________________

**Movie:**

_____________________________________________________________________________________________________

**Sport:**

_____________________________________________________________________________________________________

**Song:**

_____________________________________________________________________________________________________

**Color:**

_____________________________________________________________________________________________________

**Character:**

_____________________________________________________________________________________________________

---

SuperSibs Powered by ALSF: 333 E. Lancaster Ave, #414, Wynnewood, PA 19096
Phone: 610-649-3034   Fax: 610-649-3038   Website: SuperSibs.org
Typical Sleeping Habits:

Goes to Bed at: ______________________p.m.

Sleeps Through the Night?  ALWAYS  MOST OF THE TIME  NEVER

Wets the Bed?  NEVER  SOMETIMES  RARELY

Wakes up at: ________________________

Typical Eating Habits:

Breakfast: ______________________________________________________________

Lunch: ________________________________________________________________

Dinner: ________________________________________________________________

Snacks: _______________________________________________________________

How would you describe your child:  PICKY EATER  GOOD EATER  WILL TASTE ANYTHING

When my child is upset he/she eats:  MORE than usual  LESS than usual

My Child:

My child is typically (choose as many as necessary):  HAPPY  LOUD  QUIET  SAD  WITH FRIENDS  ALONE

Favorite item – and what he/she calls it: ______________________________________________

I know my child is stressed when he/she: ______________________________________________

I know my child is upset when he/she _________________________________________________

I know my child is happy when he/she ________________________________________________

Child’s Best Friends Names/Phone Numbers:

Name ___________________________  Phone: ______________________________

Name ___________________________  Phone: ______________________________

How you can reach me:

Hospital Name: ____________________________

Hospital Number: _____________________________

My cell phone: ____________________________