

ROM LLS

The Leukemia & Lymphoma 1. Society (LLS)



Being a teen can be tough. You're juggling school, friendships, family and more. Throw cancer into the mix? Ugh! 🙁

You're right—it's not fair.

IT'S OKAY TO BE ANGRY, SAD, SCARED OR A MIX OF MANY EMOTIONS.

Here's the good news:

Even when faced with a situation outside of your control, such as cancer, there are things you can do to take care of yourself to feel more in control. By reading this magazine, you've taken a step toward doing just that.

You have people on your team who you can ask for help. Check out page 4. Other teens have been through similar experiences. Read Julian's and Annabel's stories starting on page 22.

Many resources exist that can provide you with support and empower you. Take advantage of them.



Illustrations by Honor Hingston-Cox



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BLOOD CANCER 101

Blood cancers affect the bone marrow, blood cells, lymph nodes and other parts of the lymphatic system. Leukemia, lymphoma, multiple myeloma, myelodysplastic syndromes (MDS) and myeloproliferative neoplasms (MPNs) are all types of blood cancers. Blood cancers affect people of all ages, races and sexes.

Want more resources? Visit www.LLS.org/teens or scan the QR code for more from us and other trusted organizations!



young_adults, who have been where you are.

Try the Very Berry

Smoothie recipe on page 7!

Hear from Julian and Annabel,

Teens, ask your parents or guardian for permission before visiting or resources.

EMERGENCY PLAN

If you experience an emergency, either when you are alone or without your parent or guardian present, you need to know what to do. Save this information in your phone or keep a printed copy with you (for example, in your backpack or purse).

IN AN EMERGENCY, WHEN IN DOUBT, CALL 911.

If you are hanging out with friends, make sure your friends know to call your parent/guardian and/or 911 in an emergency if you are unable to do so yourself.

		-
		_
		_
Who should I (or so	omeone else) call in an emergency?	
 Parent or guardi 		
Name:		
Phone number(s)	s).	
Name:		
Phone number(s	s):	
 Hospital or treat 		
Name of hospita	tal or treatment center:	
Phone number:		
 Other emerge 	SUCA CONTACT	
Name:		



SET UP AN "IN CASE OF EMERGENCY" (ICE) CONTACT ON YOUR SMART PHONE

Most smart phones allow you to pick a contact in your phone (such as a parent or guardian) as your emergency contact. In case of an emergency, a friend, a bystander or first responder can call your emergency contact without needing your phone's password. To find instructions on how to set up an ICE contact, search online for "how to set up ICE on an iPhone or Android" (depending on your type of phone).



- Learn about your diagnosis and treatment options.
- 2. Ask if your cancer center has a **program or resources** for teens or young adults.
- Take your medications exactly as prescribed. Do not take more or less. Do not take any new medications, including over-the-counter medications, without checking with your healthcare team.

Don't miss appointments. Even though they can be upsetting, frustrating or even boring, they are important.

Knowledge

R_x

Prescription Medical

TAKE ONE TABLET BY

MOUTH EVERY DAY

Refills 4 ti

Follow your doctor's instructions. Doing things that your doctor has told you to avoid can be dangerous for you. Your treatment may not work as well, or you may have serious side effects.

Know your medical history and **keep records**. Every doctor you will see in the future will need to know — about your diagnosis and treatment.

Tip: Many doctor's offices offer online patient portals where you can view your medical records and more. Always ask questions. 🧲

It's your body and your health you deserve answers.

> Talk to your parent or guardian if you feel as though you are not being heard by your doctor. If the problem continues, ask your parent or guardian to consider changing to a different doctor that's a better fit for you.

Be honest with members of your healthcare team. Talk to them about mental health, tobacco, vaping, drugs, alcohol or sex. All of these can affect your overall health, and some of them can affect your cancer treatment. If it's uncomfortable talking openly about these topics in front of your parents, tell them so. Then, tell the members of your healthcare team that you want to speak to them privately.

Ask your parents to **explain your health insurance plan**. They may be handling it now, but it's important for you to learn how it works.

11. On the day that you turn 18 years old, the members of your healthcare team will ask you to make your own medical decisions and sign consent forms for your treatments. If you want to, you can sign papers giving members of your healthcare team permission to continue to talk to your parents about your medical information.



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Survivorship Workbook for Children and Adolescents

Working with your parents and members of your healthcare team, use the free LLS workbook *Navigating Life During and After a Blood Cancer Diagnosis*

to collect all the important information you will need as you move through diagnosis and treatment into follow-up care.

Visit www.LLS.org/SurvivorshipWorkbook to learn more.

111 WHO'S ON MY TEAM?=



SKILLS / 🎖 🖪 🖏 Diagnosing and treating many illnesses in children and teens and referring patients to other medical specialists

> Your pediatrician is your "primary care provider (PCP)."

PEDIATRIC ONCOLOGIST **OR HEMATOLOGIST-**ONCOLOGIST

SKILLS / 🖏 🌄 🤤

Oncologist: Diagnosing and treating children and teens who have cancer

Hematologist-Oncologist: Diagnosing and treating children and teens who have blood cancer or other blood disorders



Experiencing side effects? Let your oncologist know.



ONCOLOGY NURSE OR NURSE PRACTITIONER

SKILLS / 🖖 🛲 🗳

A)

Treating people who have cancer (Giving chemo, drawing blood, supplying snacks, wiping tears ... and more)

Got questions? Oncology nurses have answers. TIP



SOCIAL WORKER

SKILLS / 🐼 🖑 🥋

Talking to teens and their families about their emotional and practical needs and finding them support services



Social workers can connect you with other teens in cancer treatment.



SKILLS / 🏦 🖓 🕸 Helping children, teens and their families cope with cancer



Do you need help talking to your parents? Let your child-life specialist be the referee.



REGISTERED DIETITIAN

SKILLS / 🖋 🖞 🗊 Helping people improve their food choices and learn about nutrition



for snacks, even ones that can taste good when you don't have any appetite.

TEACHER AND GUIDANCE COUNSELOR

SKILLS / Č ₿ ₽ Helping teens learn, grow and navigate school

TIP

Worried about returning to school? Talk to your teacher or guidance counselor.



FRIENDS

SKILLS / 😤 🐼 🕑 Letting you be yourself and making you laugh



If you can't see your friends often, connect in other ways. **See page 20 for ideas!**



Kan Work PARENTS, GUARDIANS, AND TRUSTED ADULTS SKILLS / 🌳 🏙 🖓 Caring about you, supporting you, and giving guidance Remember, you can always TIP go to them and ask for help. SUPPORT ORGANIZATIONS Skills / 💟 🕄 🖓 Providing programs, resources and assistance for families dealing with cancer Support organizations may A offer financial assistance, TIP support groups, educational events and more. Visit www.LLS.org/OHO for a list of other helpful organizations. Teens, ask your parent or guardian's permission before visiting these resources. You may also need them to apply for support programs on your behalf.



LLS COMMUNITY

At this one-stop virtual meeting place, you can talk with other patients and get the latest blood cancer resources and information.

Share your experiences with other patients and caregivers and get personalized support from LLS staff.

Visit www.LLS.org/community to join.

People 16 years old and older are invited to join LLS Community. Ask your parent or legal guardian for permission before joining.



STAYING **WELL**

Your immune system helps fight illness and infections. Every time you get sick, your immune system goes to work to help you heal and feel better. Cancer and cancer treatment can weaken your immune system making it easier for you to get sick or get an infection.



Wash your hands with warm water and soap for at least 20 seconds, especially before eating and after using the bathroom. Avoid people who are sick.

∖ You can also use hand sanitizer

Wipe your cell phone down with disinfecting wipes.

You know where it's been!



Take care of your central line or port, as instructed by your healthcare team. Wear a mask in crowds and in waiting rooms.

Avoid activities that put you at risk for cuts, injuries and falls. Ask your healthcare team how to care for cuts.

Pets also include the non-furry kind,

such as lizards. Reptiles

carry bacteria, too!

Take precautions around pets and animals. Let someone else clean up after pets.

DO YOU KNOW THE SIGNS AND SYMPTOMS OF INFECTION

Tell your doctor immediately if you notice any of these:



- Fever of 100.4°F or greater
- □ Chills
- □ Sweating
- Redness, swelling or pain near a wound
- Diarrhea
- A burning feeling when you pee
- A cough or sore throat
- Vaginal itching or an unusual discharge
- Abdominal pain
- Pain or redness near a central line or port

Very Berry Smoothie

This refreshing pineapple, banana and berry blend smoothie has 2½ cups of fruit per serving. Makes two servings.

INGREDIENTS

- Diki
- 1 cup frozen strawberries
- 1 cup frozen raspberries
- 1 cup pineapple chunks
- 1 banana

1 cup skim milk (or almond milk)

11/2 cups ice

TIP: If you need to either maintain or gain weight, use whole milk instead or add a scoop of full-fat Greek yogurt.

DIRECTIONS

- 1. Peel and slice the banana.
- 2. Gather all ingredients and combine in a blender.
- 3. Cover and blend until smooth.
- 4. Serve right away or pour into ice cube trays and freeze.
 During the week, pop out the cubes for a quick on-the-go breakfast.

Notes: Get an additional food group in your smoothie by adding 1 cup of spinach or kale.

Source: USDA Center for Nutrition Policy and Promotion

WANT MORE RECIPES?

- Nutrition Education Services Center: www.pearlpoint.org/recipe
- American Institute for Cancer Research: www.aicr.org
- Academy of Nutrition and Dietetics: www.eatright.org
- Cook for Your Life: www.cookforyourlife.org/recipes

Smart Snacking

For a filling snack with a lot of nutrients, **combine food groups**.

For example, try:

- yogurt and berries
- carrots and hummus
- · apple and almond butter
- cheese and whole-grain crackers

Sip water or other caffeine-free fluids throughout the day to stay hydrated.

HAIR

Cancer treatment can cause hair loss, including eyelashes and eyebrows. There are people who lose all their hair, others lose some, and some people do not lose their hair at all. Most people's hair will begin growing back once their treatment ends. Here are ways to take care of your hair during (and after) cancer treatments:

- Wash your hair and scalp every 2 to 4 days with fragrance-free shampoo and conditioner. Rinse well and pat dry with a soft towel.
- Continue to comb your hair, even if you are noticing hair loss.
- If you know that your treatment is likely to cause hair loss, you may find it helpful to get a short haircut or shave your head before treatment begins. (Using an electric shaver instead of a razor will prevent cuts!)
- Use hats, scarves, caps or bandanas to keep your head warm and protect your scalp from sunburns.
- Use mineral oil or coconut oil to moisturize the scalp, especially if it's dry.
- Wear a wig if that feels right for you. You can even try a new hair color or style.
- Avoid perms, chemical relaxers, permanent hair dyes and bleach, all of which may damage the hair and irritate the scalp.



A

Locks of Love locksoflove.org

Hair We Share hairweshare.org

Wigs for Kids wigsforkids.org • Do not put hair in tight braids, cornrows or ponytails. They can cause breakage. Do not use clips or ties that hold the hair tightly.

Caring

 You can use a make-up pencil or brush to draw on eyebrows or fill in brows (or use temporary eyebrow tattoos).

MOUTH & TEETH

- Brush your teeth and tongue at least twice a day with toothpaste and a soft-bristle toothbrush.
- Ask your healthcare team if you can floss. If your blood counts are low, flossing may increase the risk of bleeding or infection. If it's safe to do so, floss gently every day.
- Braces may need to be removed before treatment to reduce the risk of infection.
- Rinse your mouth with plain water or a mixture of ¼ teaspoon of baking soda and ½ teaspoon of salt in 1 cup of warm water.
- Tell your healthcare team if your gums bleed or if you see white patches in your mouth.
- Avoid smoking, vaping and chewing tobacco, all of which irritate the mouth and increase the risk of other diseases.



NAILS

- Keep your nails clean, dry, and short because nails may darken, crack or become brittle from treatment.
- Try not to bite your nails or pick at cuticles.
- Skip manicures and pedicures at salons.
- Don't apply fake nails. They can damage your natural nails and increase the risk of infection.
- Soak hands in a natural oil, such as olive oil, to help moisturize.
- Ask your healthcare team about nail polish. Nail polish can strengthen and protect the nails. However, check with the members of your healthcare team before painting your nails, because they may want to be able to see your nail beds to check your blood circulation. Nail polish can also interfere with the clip that is put on your finger to check oxygen levels in your blood.
- If you are removing nail polish, use an oily polish remover to prevent drying.
- To protect your toenails, wear comfortable, loose-fitting shoes with cushioned socks.

SKIN

- Take a warm (not hot) bath or shower every day. Use unscented soap or body wash. Avoid bubble baths-they can irritate the skin.
- Pat skin dry with a towel. Don't rub.
- Use unscented lotion for dry skin.
- Use lip balm on dry or chapped lips.
- Avoid direct sunlight. Use a broadspectrum, water-resistant sunscreen with a sun protection factor (SPF) of 20 or higher. Reapply sunscreen every 2 hours.
- If you use acne medication or washes on your skin, ask your healthcare team if it's safe to continue using these during treatment.
- Do not pick at your skin or pop pimples. This could cause an infection.
- If you shave, use an electric shaver, instead of a razor, to prevent cuts that could get infected.

Eyebrow Tutorial

Use an eyebrow pencil within a shade or two of your hair color. If you have light hair, a slightly darker pencil may work best. If you have dark hair, a slightly lighter pencil may work best. You can also ask an employee for help at a store that sells makeup or at the makeup counter in a department store or drugstore.

Use the pencil to mark the start of the brow, the arch and the end of the brow.

- Using the marks as a guide, fill in the brow with light, hair-like strokes, tapering towards the end.
- Blend with the spoolie brush. (Most eyebrow pencils have a spoolie brush on the non-pencil end.)

Drawing on brows takes practice. Don't worry about the brows looking exactly the same. Natural brows do not match exactly.

You can also try other products such as brow powders, gels, pomades or stencils.

TIPS to manage the Solution State of Solution Stresson St

sensitivity to smells

- > Lay off the perfume and air fresheners. (You smell fine!)
- Eat cold or room temperature foods. Hot foods can be smelly.
- > Use cups with lids.

mouth sores

- Rinse your mouth often with a mixture of ¼ teaspoon of baking soda and ¼ teaspoon of salt in 1 cup of warm water.
- Brush your teeth and tongue with a soft toothbrush. (No one wants bad breath!)
- > Suck on frozen fruit or popsicles.
- Choose soft, bland foods that won't be difficult to chew and that won't irritate your mouth. (Put down the tortilla chips and hot sauce!)

diarrhea

- > Drink clear liquids such as water and sports drinks to stay hydrated.
- > Avoid foods that can make diarrhea worse such as high-fiber foods, raw fruits and vegetables, spicy foods, fatty foods and milk.
- > Eat foods that are easy to digest such as white rice, applesauce, bananas, and cooked, soft vegetables.

Always tell your healthcare team if you experience any side effects.

There may be medications that (can help you to deal with them.

dry mouth

- Stock up on sugar-free gum, candy and popsicles.
- > Keep lip balm handy.
- > Drink water throughout the day.
- Pucker up with tart foods, such as lemonade or sour candy.

nausea

- > Eat small meals throughout the day.
- Snack on dry, bland foods such as crackers, toast, cereal, or pretzels.
- > Avoid foods that may trigger nausea such as fried and spicy foods.
- > Try ginger ale, ginger candy or ginger tea.
- > Stay sitting upright after eating.
- > Don't skip meals. An empty stomach may make nausea worse. Yuck!
- > Wear **comfy**, lose-fitting clothing.
- If you do throw up, sip water, ginger ale or a sports drink to stay hydrated.

constipation

- > Eat more foods with fiber such as whole fruits, vegetables, beans, and whole grains.
- > Drink plenty of **water**.
- > Try plum or prune juice.
- > Be physically active to get things moving ... (You know what we mean!)

>> WANT MORE TIPS? Visit www.LLS.org/booklets and filter by "Side Effect Management." <<



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Acancer diagnosis does not necessarily mean you will have pain. But, it's possible that you may experience some pain.

Pain may be short lived (acute) or continue longer (chronic or persistent).

Some people with a cancer diagnosis experience pain. The pain may be bone or joint pain, tingling in the hands or feet (neuropathy), mouth sores, skin irritation, or pain due to a surgery or procedure (for example, a port placement or bone marrow biopsy).

The type of pain and its intensity depends on the diagnosis, treatment and the individual person's response to treatment. Ask the members of your healthcare team to explain the sorts of pain or discomfort you may experience and how such experiences would be managed.

PAIN CAN BE MANAGED. NO PAIN SHOULD GO UNTREATED OR IGNORED. Whenever you are experiencing pain, tell your parents or guardian and members of your healthcare team right away. You are never bothering them when you tell them you have pain. They want to help you.





Do you always want to take a nap? But then, when it's bedtime, do you find it hard to fall asleep or stay asleep? Do you feel as if you don't have the same energy levels as you did before cancer?

Sleep is important for both physical and mental health. However, many teens with cancer struggle with fatigue or sleep problems.

Talk to your healthcare team about ways to manage fatigue.

Т

Tips To Fight Fatigue

- Eat frequent small meals and snacks throughout the day to maintain energy levels.
- Drink water and other non-caffeinated liquids throughout the day to stay hydrated. Dehydration can make you feel tired.
- Stay active. Being physically active during the day can give you more energy and help you sleep better at night.
- Keep daytime naps short, 30 minutes or less.

Super Sleep Habits

- Go to bed at the same time every night.
- Do something relaxing before bedtime.
 Take a warm bath, read, do some journaling, meditate, or listen to calming music.
- Keep your bedroom cool, quiet and dark.
- Avoid caffeine (coffee, soda) at least 6 hours before bed.
- Stop using screens at least an hour before bedtime. This includes cell phones, computers, tablets, hand-held video games and televisions.

BE KIND 🔏 TO YOURSELF.

You may not have the energy to do all the things you did before your cancer diagnosis. That's okay!

Set realistic goals. Focus on the things that are the most important to you. Ask for help when you need it.



Nutritious foods give your body the energy it needs to recover from treatment, but during cancer treatment, you may not always feel like eating. (*Thanks, chemo.*) Or, you may have cravings. (*Thanks, steroids.*) Treatment may make food taste different. Even your favs may not seem appealing. When you are in the thick of treatment or dealing with side effects, don't stress about eating the "right" or "healthiest" foods. Eat foods that sound good to you. When you feel well, eat a variety of nutritious and delicious foods.

Wash fruits and veggies before cutting and eating!

Choose

whole grains a great source of energy!

> Eat a variety of colorful vegetables and fruits for the most beneficial nutrients.

- Avocado, olive oil and nuts are good sources of healthy fat!

Make at least 213 of your meal plan

plant proteins such as beans, peas, nuts and tofu.

Try



and fries

Fried food Red such as such chips stea

Red meatSaltsuch assuch assteak andtable salt

hamburgers

LIMIT THESE FOODS

and most

packaged foods Processed meats such as hot dogs and bacon

Keep It Clean

- Wash your hands before cooking or eating.
- Keep raw meat away from all other foods and surfaces.
- Cook meat, chicken, fish, eggs and leftovers all the way through.
- Close the refrigerator door!
 Keep cold foods and leftovers cold.
- Check the expiration date.

If a food looks, smells or tastes weird, throw it away!

High-Risk Foods

If you are at risk of infection due to low white blood cell counts, you need to avoid foods associated with foodborne illness (food poisoning). A few examples include sushi, undercooked meat, raw or runny eggs, cookie dough with raw flour and/or eggs, and unpasteurized foods. **Ask your healthcare team for nutrition guidelines.**

Want more nutrition information? Visit www.LLS.org/booklets to view the free LLS booklet Nutrition Handbook.

What You Need to Know

Puberty

As you probably learned in a health class *(or during an awkward conversation with a parent)*, during the preteen and teenage years, people go through many physical and emotional changes. An increase in the production of sex hormones prepares the body for adulthood and for the ability to create a baby. This time in your life is called "puberty."

ancer

Honestly, your body is going through a lot of crazy changes. You are going through puberty and undergoing cancer treatment, both at the same time! It's normal to feel uncomfortable, confused or annoyed by this onslaught of changes. Remember, they are nothing to feel embarrassed about. Easier said than done—but it's true!

One thing to keep in mind, cancer treatment can sometimes delay or interrupt puberty.

Talk to your parents, guardian or your healthcare team if you have questions or concerns about puberty.

You might cringe at the thought of talking to members of your healthcare team about puberty, periods, or sex, but medical professionals talk about this kind of stuff all the time. It's a very normal conversation for them.

Periods & Cancer: What You Need to Know

- If you have a period, cancer treatment may interrupt or stop your cycle. Even if this happens, you may still be able to become pregnant if you are sexually active. Pregnancy during cancer treatment is often not safe for the pregnant person or the fetus.
- If you have a low platelet count, your period may be heavier than usual. Use pads or absorbent underwear during your period, as tampons can cause small tears to your vaginal walls.
- If you have a low white blood cell count, use pads or absorbent underwear during your period, as tampons pose a risk for infection.

Ask your healthcare team what to expect and let them know about any changes you experience.

ERTILITY. WHAT You NEED TO KNOV

As a teen, you may not know yet if you would like to be a parent in the future. That's okay. But because of your cancer diagnosis, it may be something you need to think about.

What is "fertility?"

"Fertility" is the ability to have a biological child, a child who carries your DNA (your genetic material).

Cancer treatment can affect fertility making it either less likely or more difficult to have a biological child in the future.

How does cancer treatment affect fertility?

Cancer treatment can damage organs that are part of the reproductive system. This can include the ovaries (where eggs are stored), the uterus (where a fetus grows and develops) or the testes (where sperm is made). Cancer treatment can also damage the thyroid or pituitary gland. These organs produce hormones that support growth and sexual development (puberty).

What else do I need to know?

Many cancer survivors do go on to conceive (become pregnant or contribute to a pregnancy), and carry and deliver healthy children. Some people do so by taking steps to preserve their fertility before starting a treatment that may affect fertility.

Remember, there are many ways to build a family and many ways to have children, whether through natural conception, with medical assistance, or adoption. When, and if, you decide to have children in the future, consider and discuss all options.

What do I need to do?

Ask your healthcare team if your treatment will affect your fertility and if so, ask about your options to preserve your fertility.

Note:

Even if you have been told cancer treatment may affect your fertility, you may still be able to become pregnant or contribute to a pregnancy. If you are sexually active, always practice safe sex. Use a form of birth control to prevent pregnancy. Use a barrier method (condoms, dental dams) to prevent sexual transmitted infections (STIs), also called "sexually transmitted diseases (STDs)."



Try moving from Cat-Cow to Bird Dog to Downward Dog for a simple yoga flow.

4 Tree Pose

Start by standing with your arms at your side.

Reach down and hold your left foot.

Use your hand to bring your left foot up along your right thigh. (a) If you find it difficult to balance or lift your leg, try this instead: Rest the heel of your left foot on your right inner ankle. (b)

Find your balance by focusing on something a few feet away from you.

Bring your palms together in front of your chest.

Hold for a few seconds and focus on your breathing.



6 Reclined Spinal Twist

Start by lying on your back with your arms out.

Bend your right knee and place your right foot on your left knee.

Let you right knee gently fall over to the left side of your body.

Look at your right hand.

Hold for a few seconds and breathe deeply.

Switch to the other side.

Start by standing with your legs further apart.

b

Bend your left knee at a 90° angle. Keep your knee over your ankle.

Stretch your right leg out.

Spread out your arms and look at your left hand.

Hold for a few seconds and focus on your breathing.

a teen's guide 17

With your parent's or guardian's permission, you can search online for more poses!



Want to take it up a notch?

Consider adding light weights to your movement such as holding a weight while doing warrior II pose or walking.

You can find objects around the house that you can use as weights, such as an empty milk jug filled with water or a soup can.

Check with your doctor to make sure these movements (and ones like them) are safe activities for you as you go through cancer treatment.





Do you have a social worker and/or a child-life specialist as a member of your healthcare team? Social workers and child-life specialists are healthcare professionals who can help you (and your family) to cope with your emotional or practical needs. They can also help you find support services. You can always share your concerns with a social worker or child-life specialist and ask them for answers if you have questions!

Q. A friend that I met at a cancer support group isn't doing well. While I'm glad my treatment was successful, I feel bad for them. How do I handle these feelings?

A. It is normal to feel this way. Sometimes people even give this feeling a name—"survivor's guilt." This can be the guilt, remorse or sadness people feel when their circumstances seem to be more favorable than those of another person in a similar situation. In reality, you don't have control over your friend's response to treatment, and it is not your fault. Even though this feeling is normal, it can really make you feel sad and impact your life. A way to help with these feelings is to talk about them and process them with someone who understands. Talk to a mental health professional, a social worker or a psychologist, for example. Consider sharing these feelings with other members of your support group. It is important to know that you are not alone.

Q. I will be starting a new school next year and meeting new people. How do I tell people about my cancer diagnosis? Do I have to tell people?

A. Meeting new people who don't know what you've been through can be anxiety-provoking and make you want to isolate. It can also be an opportunity to experience new things and get to know new people. You don't have to tell someone about your cancer diagnosis, unless you want to. If you choose to share this part of yourself with others, you may want to share some details, but not all the information. It is perfectly fine to set boundaries and limit who you tell and what you tell them. You can also do this at your own pace, when it feels right to you. You do not have to tell someone about your diagnosis the first time you meet them. Some people find that they are more comfortable talking about their cancer diagnosis if they have practiced talking it out with a close friend or family member beforehand. Anticipate that people will have different reactions;

anticipate that they may ask a lot of questions. It may be helpful to think through your answers. You can also ask other teen cancer survivors how they handle telling people about their diagnosis. You can meet other teens in a support group or at a survivorship camp or conference. You should know, though, that some staff members at school may need to know about your diagnosis to help support you. If that is the case, members of your healthcare team, such as a social worker or child-life specialist, can help guide you and your parents or guardian about communicating with school staff members.

Q. Do I have to tell someone who I'm dating or someone I have a crush on about my cancer diagnosis? What if it changes how they feel about me?

A. Dating can be intimidating no matter your situation. You don't have to tell someone about your cancer diagnosis, unless you want to. (See answer to the last question.) Keep in mind, though, that if someone will be playing a big role in your life or is someone you will be going to for emotional support, it's good to be honest and up-front with them. When, and how, you tell someone is always your choice. When it comes to dating, some people prefer to disclose their cancer diagnosis right away to clear the air and get a sense of whether the other person is likely to be supportive or not. Some people prefer to wait until they trust someone before they share their cancer diagnosis. If your

date reacts negatively, it is not your fault. You are not your cancer diagnosis. You are a person with many different thoughts, feelings and interests. People have different histories and encounters with cancer. In some cases, you may be able to teach someone what it means to be a person with a cancer diagnosis. For example, you may need to explain that they can't "catch" cancer from you. It isn't contagious like the flu. In other cases, someone may not be hearing you. You may have to move on. It may hurt but, in the long run, anyone you are going to allow to have a special place in your life must be caring and supportive.

Q. I won't be able to go to the prom with my friends because of treatment. I feel left out and robbed of the experience. I just want to be a teen. What can I do?

 \mathbf{A} . This is really hard. It's unfair that you have to miss the prom while your friends will be having fun. It is so difficult to have to prioritize your health when you just want to be a teen. Missing this experience will be really sad--but try to think of ways to make it a little bit easier. Can you get dressed up with your friends and take pictures before the prom? Is there something special you want to do on that night instead? Maybe you can have a party with your friends at another time when you're feeling better? It's important to talk to the supportive people in your life—close friends, family, other survivors, counselor or social worker-about how you are feeling.

They might have some helpful feedback and ideas about how to get through something like this.

Q. I am afraid of the future. I try to talk to my parents about it, but they tell me not to worry. I still worry. I feel pressure to be positive all the time. How can I make them understand?

A. Many people who have cancer, especially young people, feel that they always have to "stay positive." This can be helpful for some people, but it is not realistic to expect you to have a positive attitude all the time. You can still be a strong person but feel sad, angry, anxious and vulnerable at times. That is part of being human. It is very normal to worry about the future. After all, no one can tell you what the future may hold; but fears about the future can make it hard to live your life in the present. If possible, talk to your parents about the ways in which these worries are impacting your life. Ask if you can meet with a counselor. social worker or some other mental health professional who can help you to process your fear. You can also tell a member of your healthcare team that you are afraid of what the future could hold for you. They might be able to help you reframe some of your worries, or they may suggest someone you can talk to.



Check Out These Organizations for Teens and Young Adults



ELEPHANTS AND TEA elephantsandtea.com Free quarterly magazine, digital programs and events



STUPID CANCER stupidcancer.org CancerCon (annual conference), events, webinars and list of resources



TEEN CANCER AMERICA teencanceramerica.org Stories, videos and list of resources

FRIENDS



STAYING IN TOUCH

- Catch up through video calls
- Stream a movie or play a

SOCIAL MEDIA



TALKING TO YOUR PARENTS OR GUARDIAN

After your diagnosis, does it feel as though your parents are babying you? Do you wish they would let you do more for yourself?

Talk to them. Do it when you aren't upset or frustrated. Start by thanking them for all that they do. (Admit it—they do a lot for you!) Then name a few specific things that you would like to change. For example, "I prefer to clean my room myself."

Still struggling to communicate with your parents or guardian? Ask a child-life specialist or social worker for help. They are pros at navigating tough conversations!

BEWARE OF HEALTH INFO ONLINE!

It's best to avoid Googling cancer. With the internet, so much information is available right at our fingertips. But it's not all reliable information. The best source of information about your diagnosis and treatment plan is your healthcare team. Members of your healthcare team can answer your questions and tell you where to find reliable information if you want to read more.

WHAT IF A FRIEND **GHOSTS ME?**

have experience with



or see each other. This may leave you friends who do stick around or step up.

TREATMENT DAY Style

On treatment or appointment days, **COMFORT IS KEY**. You can have fun too. Wear your favorite colors or prints such as plaid, polka dot, or camo. You can support your favorite team or rock a band T-shirt.

YOSEMITE

Loose or

V-neck

T-shirts

easier for members of your healthcare team to access your port

so it's

A cozy cardigan, zip-up sweatshirt or button-up flannel. Dress in layers!

Sneakers

or slippers

with a

hard sole

Socks! Cold toes

are the worst.

WHAT'S IN MY BAG?

Knit hat or scarf to keep your head warm

Pack a few key items in a **tote, backpack or purse** to take with you on treatment (or appointment days. A **blanket** will you keep you warm in a chilly hospital. A few favorite **snacks** and a reusable **water bottle** will keep you fueled and hydrated. **Hard candy** or **sugar-free gum** can help if your mouth feels dry. *Yuck!* Take a **phone, tablet**, or **laptop** and **headphones** so you can listen to music or binge watch a new show (*or a show you've seen a million times—no judgment*). Don't forget a **charger**—you'll thank yourself later. For more ways to pass the time, bring a **book, journal** or **deck of cards**. You could even bring **homework**. (*But we don't blame you if you don't.*) Add a **comfort item**, such as a stuffed animal or favorite pillow. Lastly, toss in **lip balm** and **unscented lotion** to soothe dry lips or skin.

Sweatpants, leggings or

even pajama pants

Julian's STORY

KEEP SETTING BIG GOALS

I was a 10-year-old kid when I was first diagnosed

with leukemia. I was a happy, energetic kid who loved being outside, and I was a straight-A student. However, my whole childhood was put on hold once I had cancer. Rather than having sleepovers at my friend's houses, I was sleeping over at the hospital. It was hard losing my energy, smile, confidence, and hair as treatment took over my life. As a kid, it was hard to truly understand what was happening between getting injections, procedures, chemotherapy (chemo) and surgery. All I knew was that everyone around me was crying and sad. I was just going through the process blindly and trying to get better.

After almost 4 years of chemo, I was finally in remission. At this point, I was a quiet 14-year-old in junior high, barely starting to build my confidence back as my hair grew back. I was beginning to feel my age again. I spent most of my time in school rather than in the hospital, which was a significant change of scenery. I was doing well in school once again.

In high school I joined the cross country and track team. I loved running because it was always a way for me to let go of all the anger, frustration, sadness, and other feelings. My confidence grew. During my sophomore year, I had huge goals— I wanted to run a mile in under 5 minutes, and I planned to take part in a college engineering program over the summer.

Before summer came, I went for a checkup, and my doctors told me the



cancer might be back. I was terrified. My life had just returned to normal. At the age of 16, a bone marrow biopsy confirmed that my leukemia had come back in full force, and I would need to start treatment right away.

A **bone marrow biopsy** is a procedure to remove a small amount of bone marrow for testing. Bone marrow is the spongy center located inside the bones, where blood cells are made.

THE BLOODLINE WITH LLS

s here to remind you that *after a diagnosis* comes hope.

Listen in as patients, caregivers, advocates, doctors and other healthcare professionals discuss diagnosis, treatment, side effects, resources and more.

Visit www.LLS.org/TheBloodline to listen to the podcast.

Learning that I had leukemia for a second time was so much more devastating, not just because I knew what I had to go through but also because it had taken me so long to just feel normal again. I felt like cancer was putting all my dreams and goals on hold.

My doctors told me that I would need to go through the same treatment that I went through as a kid, another 4 years of treatment. I started chemotherapy and lost my hair again.

Soon after I started chemo, my doctors realized that my body had built up a tolerance to the treatment, so it wasn't as effective. Instead, a bone marrow transplant would give me the best chance of remission. I was admitted to the hospital for my transplant.

A bone marrow transplant, also called a "stem cell transplant," is a procedure that replaces unhealthy bone marrow with healthy bone marrow to create new blood cells.

First, I went through 1 week of highdose chemo and radiation to wipe out my bone marrow and prepare me for my transplant. All I wanted to do was sleep, and the chemo caused bad mouth sores. After the transplant, I recovered in the hospital. It was difficult to spend almost 3 months away from

home. My mom stayed with me at the hospital, and I was grateful to my family for being so supportive of me. Overall, my transplant went well, and I returned to high school for the second half of my junior year.

After my transplant, I was ready to make the most of my second chance. I knew I wanted to do something to support other patients. I wanted to give them hope like my family, friends, healthcare team and others gave to me. So, I started selling bags of chips. My friends started helping too. With the money, we made 50 care packages for children in cancer treatment. My senior year, we did even more fundraising. I was lucky to have many great friends who supported me and my mission.

Once I turned 18, I officially founded the Bags of Love Foundation, an organization dedicated to providing hope to children, teens, and young adults affected by cancer. Our programs include care packages, scholarships, and financial assistance. As an organization, we have raised over \$100,000 for other patients affected by cancer. My ultimate goal is to provide hope to patients and families nationwide.

Julian Castaneda, age 22 In addition to his work with Bags of Love Foundation, Julian is also a student at California State University, Northridge and a Dare to Dream Ambassador for • The Leukemia & Lymphoma Society (LLS).



Check out Julian's Bags of Love Foundation at bagsoflovefoundation.com to learn more!

Bags of Love



MEET THE DARE TO DREAM PROJECT ...

The goal of The Dare to Dream Project is to transform treatment and care for pediatric blood cancer.

Visit www.LLS.org/DareToDream to learn more about what LLS is doing to achieve this goal and how you can get involved.

P R O 1 F C



Annabel's STORY

CURIOSITY, CONFIDENCE AND MENTAL HEALTH



near my clavicle. I did not have other symptoms, but I went to my family doctor to have it checked out. My doctor thought the lump was a lipoma (a non-cancerous tumor) and ordered an ultrasound to check it out. I am interested in medicine, so I was curious about the diagnostic process.

During the ultrasound, the ultrasound tech took a long time to complete the scan. She kept adding gel and moving the wand up my neck. I began to suspect something was wrong. I had a CT scan (CAT scan) next, and it showed multiple growths in my body. My doctor didn't tell me it was cancer at this point, but in my head, I knew it couldn't be anything else. I knew a benign tumor wasn't going to spread to other places. I had a biopsy to confirm the diagnosis—Hodgkin lymphoma.

A **lymph node biopsy** is a procedure where a doctor removes either all or part of an enlarged lymph node for testing. **Lymph nodes** are small bean-shaped organs that contain white blood cells, which fight infections.

At the time, after my diagnosis, I wasn't worried or depressed. I was interested from a medical perspective to see what happened next. I approached treatment with curiosity and took it head on. I am usually a positive, bubbly person, but cancer treatment is not bubbly or fun at all. Since I was 18, I was treated at an adult cancer center. I was always the youngest person there. For treatment, I got the full package. I did six rounds of chemotherapy and 2 weeks of radiation.

I had planned to shave my head when I graduated school, so I wasn't too worried about the hair loss. I called my chemo hairstyle "kiwi hair" because I still had some hair left. I decided I wasn't going to hide, and I lived my "main character moment" with confidence.

I also lost weight during treatment and then gained it back quickly when my appetite returned. Other people noticed and made comments. I saw myself in the mirror every day. I didn't really notice the changes much. When I would see people who had not seen me in a few months. I could see the shock on their faces. It was difficult to deal with. Their reactions and comments made me feel insecure and bothered me more than I thought it would. It's something I am still working though. It's a process, but I feel like now I am much happier with my body, no matter how it looks. I know my body is so strong because of all that it handled.

After my diagnosis, I was determined to finish school with my classmates. Due to the Covid pandemic, everything was online, so I was able to keep up with lessons. School kept me going. Staying busy kept me from dwelling on what was happening to me. I graduated on schedule!

My social life, however, was put on hold. Treatment weakened my immune system. Especially with Covid, going out was extra dangerous for me so l stayed isolated. It wasn't a nice feeling to see people going out together when I was stuck at home. My family and friends were my support system. My relationships with my close friends grew stronger. We had weekly, virtual check-ins to stay in touch and through this learned more about each other. I learned to value my close friends more and to filter out other people who don't matter. I've carried that lesson with me.

I am now in remission. I am in university, and I am still very interested in medicine. I plan to become a surgeon. Looking back, I wish someone had told me to look after my mental health. My doctors were really focused on my physical health, but mental health is also so important. Even 2 years later, I am still processing all of it and dealing with the emotional baggage. My advice to anyone diagnosed with cancer is to talk to a therapist early, or at least soon after treatment, if you have the strength.

Annabel Nelling, age 20

Annabel is currently studying medicine at Tartu University in Estonia and living her best life.

TALK to



members of your healthcare team about your mental health. Ask for a referral to a therapist or counselor. Learn more about mental health on page 26.



	SNACK TOTAL SACK TOTAL SACK MATCHING AND
What is your favorite color? a) Blue b) Yellow c) Red	Where would you go on a dream vacation? a) Mountains b) Beach c) Amusement park
	rite subject in school? English Math Science
What do you like to do to pass the time in waiting rooms?	What is your favorite animal? a) Dog b) Elephant c) Tiger
st. You can make anyone smile.	Mostly As: Apple juice. You are a classic—loyal and d Mostly Bs: Cookie. Fun and sweet describes you bes Mostly Cs: Ice pop. You are cool—what else is there t

Mental health (like physical health) is important to your overall well-being.

You may experience feelings of sadness, anxiety, anger, grief or guilt. These feelings are normal. Most people feel them at some point.

Find an outlet for big feelings such as:

Journaling • Music, drawing or painting • Hobbies such as reading, baking or video games • Walking or being outdoors



If these feelings begin to be scary or overwhelming, talk to the members of your healthcare team and your parent or guardian. Ask for help.

Talking to a therapist or mental health professional can be helpful for anyone. A therapist can provide you with tools that will help you to identify and cope with your emotions in a healthy way.

Visit **www.LLS.org/booklets** to view the free LLS booklet *Managing Stress:* How stress affects you and ways to cope and order the Write It Out journal.

If you are having trouble coping and do not know who you can turn to for support, **dial 988** to talk to a community crisis center representative. The 988 Suicide & Crisis Lifeline is free, confidential and always available. For the Crisis Text Line, **text HOME** to **741741**.

Do you feel as though you are spinning out of control?

First, close your eyes, take a few deep breaths and count to ten slowly. Open your eyes and list and touch the items around you.

Next, after you feel more grounded, talk to a parent or trusted adult.

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BODY IMAGE & SELF-ESTEEM

Almost everyone struggles with body image and self-esteem at some point, but teens who have a cancer diagnosis face the uniquely awful combo of cancer treatment and puberty. Yikes! Both can change how your body looks and feels in a lot of different ways.

🕴 🖡 WAYS TO FEEL MORE COMFORTABLE IN YOUR BODY 🕴 🖡

comfortable clothes. Clothes should fit your body. Your body does not need to fit clothes



Move your body. Stretch, go for a walk



Stop scrolling social media! Don't let all those "perfect" images make you feel badly

about yourself. Besides, they are all edited!



Ask friends and family members not to talk about appearance or body size. There are more interesting things to talk about!

Don't body-

shame yourself.



Your appearance does not determine your worth. You do not have to love everything about your body, but you do need to respect and care for it.

Remember, too, that you are not your cancer diagnosis. t does not define you.

Use *journaling* to work through your feelings.

Respond to these body image prompts.

 List three or more important things your body can do.

Example:

My arms can hug my friends.

List three or more things you like about yourself.

Examples: Sense of humor, smile

and intelligence

When do you feel the strongest?

For more writing prompts, visit www.LLS.org/booklets to order the FREE Write It Out journal.





You may be excited, worried or a mix of both of these feelings about returning to school. If you have any particular fears or you're feeling anxious, talk to your parents, guardian, members of your healthcare team or a teacher.

Teach Your Classmates About Cancer

By now, *you're the expert!* Before you return to school, it may be helpful for your friends, teammates or classmates to learn about cancer. (Not the whole school—just close friends.) A teacher, guidance counselor or other adult can lead the discussion. You can be part of the discussion or not. The choice is yours. Your friends care about you and learning about your experience can help them support you. An adult you trust or a member of your healthcare team can help with the discussion and provide information.

Questions, Questions, Questions

Be prepared for questions about your diagnosis. You can share either as much or as little as you want. Most questions will be from people who care about you or who are curious about cancer. If someone asks a question you don't want to answer, you can say, "I'd rather not talk about that. Let's talk about something else." If someone persists after you've asked them to stop, end the conversation and tell an adult about the problem.



Struggling with School Work?

Since cancer treatment, do you find yourself forgetting things? Is it harder to focus in class? Do your thoughts sometimes feel "foggy?"

You may be experiencing a side effect of treatment that many cancer survivors call "chemo brain." Doctors call it "cognitive (thinking) changes." Cognitive changes are common, and they can differ a lot from person to person.

If you find yourself struggling with your schoolwork, let your parent, teacher and healthcare team know. You may benefit from extra support at school. You may even be eligible for accommodations that are protected by law.

	STUDY TIPS
	Stay organized. Find a system that works for you.
	For example, try using a different color notebook or folder for each subject.
•	Keep track of due dates and tests in a digital or paper planner.
•	Review the notes you take during class later the same day to help retain what you learned. Try to review your notes on a fifth
	Don't wait and try to cram the day before a test.
•	Ask your teacher if you can record lessons. You can then listen to them later.
	Ask for help. If you have questions, ask your teacher. For help studying, osk a parent or classmate to quiz you
	isk a parent or classmate to quiz you.
4	bet aside time specifically for studying. Try to study at the same time every day
D	reate a study space, such as a desk or kitchen table.
	o not study in the place where you rest, for example, your bed.
R	t arvay distractions, such as your cell phone. Log out of social media.
	ve a snack and beverage before studying.
Tal	ce a break and move around every 30 minutes (or more often if you need to).
No	n't retaining any new information. It would be beth
0	n't retaining any new information. It would be better to get a good night's sleep.
1	DID TU
	YOU Scholarships are available to help cancer survivors pay for education. KNOW Visit www.LLS.org/scholarships to view of the Wisher
	Visit www.LLS.org/scholarships to view a potential list.



As a teen, you will need to make tough decisions—it's part of reaching adulthood. You need information to make these decisions. This information (no judgements!) is being provided for your safety and well-being.

From health class, you may already know ...

- Alcohol, drugs, vaping and tobacco can increase your risk for disease, such as heart disease, stroke and some cancers.
- Alcohol and drugs impair your mental and physical capabilities putting you (and others) at risk for injury or other dangerous situations.
- Alcohol, drug and tobacco use is illegal for people under 21 years old in the United States.
- Sex, especially sex without protection, can lead to pregnancy and sexually transmitted infections (STIs), also called sexually transmitted diseases (STDs).

By now, you may be sick of hearing this, but CANCER CHANGES THINGS. You and your peers all have issues to deal with, but you have more. It is important to keep this in mind when you are faced with tough decisions.

ALCOHOL, TOBACCO AND DRUGS

Alcohol and drugs may not mix with your medications or treatment. Mixing them may make side effects worse, treatment less effective, or cause serious complications. Smoking, chewing tobacco or vaping can also make mouth sores or taste changes worse. Smoking marijuana can put you at risk for a serious fungal infection.

SEX

Cancer treatment can weaken the immune system which puts people at a higher risk of infection, including STIs. Additionally, it can be more difficult to treat or manage an STI during cancer treatment.

Pregnancy during cancer treatment can be unsafe for both the pregnant person and the fetus.

Sexual activities may be unsafe during cancer treatment. For example, a patient who is at risk for bleeding issues due to a low platelet count may need to refrain from vaginal and anal sex.

Sexual activities may also be unsafe for your partner if you've recently received treatment because chemotherapy and other drugs can be present in your bodily fluids, including saliva, semen or vaginal fluids.

If you are sexually active, you must:

- □ Use condoms, or another barrier method, to protect against STIs.
- □ Use some form of birth control. (Do not make assumptions about your ability to become pregnant or contribute to a pregnancy.)
- □ Ask your healthcare team if it is safe to have sex or participate in other sexual activities.

Talk to your healthcare team about sensitive subjects such as tobacco, vaping, alcohol, drugs and sex. Be honest about alcohol, tobacco and drug use. Be honest about sexual activity. If you want to talk to members of your healthcare team without your parents or guardian in the room with you, ask to speak to them privately.

GETTING READY FOR HEALTHCARE

As you get older, you will transition into the adult healthcare system. Once you are 18 years old, you are legally in charge of your own healthcare. Your doctors can only talk to you about your health unless you give permission for them to talk to someone else. If you are still seeing a pediatrician as your primary care provider (PCP), between ages 18 and 22, you will be moving on to seeing a doctor who takes care of adults. (As a teen cancer survivor, however, you may continue seeing a pediatric oncologist for years after treatment ends

at a survivorship clinic for specialized care.) You will also need to learn how to manage your health by doing things like scheduling appointments and getting your prescriptions filled. (See "11 Tips to Advocate for Your Care" on page 3.) Talk to your pediatrician or other members of your healthcare team. They can help you with transitioning to adult healthcare and recommend doctors.

Visit Got Transition at https://gottransition.org/ to learn more.

Did You Know?

Cancer treatment can cause side effects that appear after treatment ends, even years later. These are called "late effects." As you get older, you may need special tests or screenings to check for these late effects. **Ask your oncologist about the possible late effects of your treatment and for screening recommendations.** When you see a new doctor (even as an adult), tell them about your diagnosis, treatment and risk for late effects to make sure you get the tests you need.

The Children's Oncology Group (COG) provides guidelines for monitoring late effects.

- For Healthcare Professionals: Long-Term Follow-Up Guidelines for Survivors of Childhood, Adolescent and Young Adult Cancers
- For Patients and Families: "Health Links," a set of materials

Visit www.survivorshipguidelines.org to download.

Check out the Health Links with your parent or guardian. Write down any questions you have for your healthcare team.









Finishing cancer treatment does not mean that your life immediately returns to being exactly the same as it was before cancer. You will still need to get regular check-ups. You may still have side effects from treatment or need to take medication.
You will be transitioning from seeing members of your regular treatment team to seeing a new team at a survivorship clinic.
You are likely to have new perspectives on a lot of things as well as new goals. You may have emotions that you are either still processing or need to process. Cancer treatment pulls the rug out from under you. Give yourself grace as you find your footing again. Ask your parents or guardian and members of your healthcare team for help whenever you need it.



Want to Learn More About Blood Cancer and Treatment?

Visit **www.LLS.org/booklets** to view, download or order booklets and fact sheets about different blood cancer diagnoses and treatments.

Visit **www.LLS.org/education-videos** to watch education videos about blood cancers, treatment, survivorship and more.



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GAME YOUR WAY AND GIVE BACK.

Every time you boot up a favorite game, you could be helping LLS fund groundbreaking treatments and top-notch care for blood cancer patients and their loved ones. Turn a family game night or an afternoon with friends into something bigger a chance to change lives.

Help us #TiltCancer!

Visit www.LLS.org/TiltCancer to learn more.

PARENTS AND GUARDIANS:

For more information on disease, treatment, support and resources, call an LLS Information Specialist at **800-955-4572**.

Thank You

to the young adults and teens who helped make this resource Possible!



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The mission of The Leukemia & Lymphoma Society (LLS) is to cure leukemia, lymphoma, Hodgkin's disease and myeloma, and improve the quality of life of patients and their families. Find out more at www.LLS.org.