

THE VIEW FROM UP HERE

Young adult guide to surviving childhood cancer





“Fighting cancer is a tough battle, but once the victory bell is rung, every survivor becomes a champion in their own right.”

Phillip, Ewing's Sarcoma Survivor

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INTRODUCTION



TO THE SUMMIT AND BEYOND

You have embarked on a very personal journey. You are a survivor. Childhood cancer survivorship begins the day you are diagnosed and lasts a lifetime. Throughout this journey, you'll face many uphill battles, physical struggles and emotional hurdles that are bound to alter your perspective. But like any challenging climb, sharing the experience will help you overcome these challenges along the way.

This guide is filled with relevant information, designed to help at every stage of your survivorship journey. Whether you were recently diagnosed, are in treatment or in remission, you are standing at the summit of a great mountain that over 500,000 other childhood cancer survivors have faced. You are not alone.

You're bound to have questions or need a little support. At The National Children's Cancer Society (NCCS), we're here to help. Call our Beyond the Cure Survivorship Program any time at 800-5-FAMILY (800-532-6459). Or visit us online at theNCCS.org. Your climb as a survivor is difficult, to say the least. Yet, as you integrate these experiences into your life, we hope you'll find ways to marvel at the true and infinite beauty within your view.

INTRODUCTION



HOW TO USE THIS GUIDE

“The View From Here” was written to help teen and young adult survivors of childhood cancer throughout the survivorship journey. It’s a long road and it’s a lot to take in. But we’ve included information that relates to the different aspects of your life—from emotional struggles and spiritual growth, to health insurance, school and relationships.



It always helps to know other people who have gone through similar experiences as you. On many pages of this guide, you’ll find “Straight talk from other Survivors,” a section that will give you ideas on how others have coped with their personal journeys. Learning how other young adults dealt with these struggles can give you great practical information that isn’t always available in medical books or online. The experiences of other survivors will help and inspire you throughout the different stages of survivorship. Always remember, you are never alone.

To learn more, visit us online at theNCCS.org.



KEEPING YOUR PAST IN THE REAR VIEW MIRROR

Part of embracing your survivorship is learning to optimize your life-long health. While you may be cured or in remission from your cancer, it's important to be in tune with your current health, as well as your history. You'll need to get good follow-up care and be aware of the potential late effects of your cancer treatments.

It's not uncommon for survivors to just want to put their diagnosis behind them and not talk about their cancer. Even if it's uncomfortable, you must discuss your cancer diagnosis and treatment with your doctor. Now is the time in life to take responsibility for your survivorship. Your long-term health depends on it.

THE 411 ON LATE EFFECTS

As the number of childhood cancer survivors continues to grow, so does the available information about late effects. The Institute of Medicine (2003) defines late effects as "complications, disabilities or adverse outcomes that are a result of the disease process, the treatment or both."

Studies have shown that two-thirds of young adult survivors report one or more chronic late effects and of that group, one-third report severe or life-threatening late effects. Many factors affect your risk for late effects. These include your diagnosis, your age at the time of diagnosis, gender, treatments and complications, as well as family history, health prior to diagnosis, and your overall health. Some late effects are more visible, such as the amputation of a limb or the removal of an eye. Others will require testing to diagnose and may occur at any time.

HOLDING WORRIES AT BAY

Getting follow-up care can cause young survivors some stress. Anxiety over the cancer returning or beginning to see new late effects is normal. Keep in mind, only a small number of survivors incur serious late effects. Research is ongoing and has the potential to reduce or prevent many late effects if you experience them. Practicing preventive medicine and maintaining a healthy lifestyle are your best defenses for reducing your overall risks. But more than anything, stay educated. The body of information about childhood cancer is continually growing. Keep informed using our Late Effects After Treatment Tool (LEATT) at theNCCS.org.



"I really liked that the LEATT was specific to my exact cancer and treatment regime and that I could click each potential problem and learn more about each one. The process was easy to do and I learned a lot of new information that was extremely helpful. I can most definitely use this information by making sure that I pay closer attention to these potential problems."

Ali, Hodgkin's lymphoma survivor



MEDICAL HISTORY: KNOWLEDGE IS POWER

Knowing your medical history is the key to maintaining good health and achieving the best possible quality of life. As you gradually take on more responsibility for your health information, you also become better able to determine whether a symptom may be linked to side effects of therapy.

Keep accurate, well-written medical records. The following information should be included:

- Previous and current medications
- Place of treatment
- Names and numbers of treatment providers
- Your specific diagnosis, including stage and location of cancer
- Date of diagnosis
- Dates and duration of treatment
- Number of relapses and dates of relapses
- Copies of any pertinent X-rays, MRIs and CT scans
- Your specific treatment: (not all treatments will apply to you)
 - 1) **Chemotherapy** (drug, dosage total, frequency and modality)
 - 2) **Surgery** (date and type, including placement of central line catheters)
 - 3) **Radiation** (area and total dosage)
 - 4) **Date and type (autologous, related or unrelated allogenic) of bone marrow or stem cell transplant**, as well as treatments in preparation for any transplants, if applicable.
 - 5) **Any complications and/or side effects during treatment and follow-up recommendations**

FOLLOW UP AND FOLLOW THROUGH

Once your status changes from “cancer patient” to “cancer survivor,” it is still very important that you maintain oncology follow-up visits, get yearly physicals and regular examinations to maintain good health. Reviewing information on late effects with your healthcare team can lessen feelings of anxiety and prevent over-testing down the road.

Follow-up visits may include routine check-ups with other sub-specialists, as well as annual visits to a late effects clinic. These annual visits give you access to a multi-disciplinary team at a major medical center. The team may include a physician specializing in long-term follow-up care, a nurse, psychologist, a dietician, a school liaison, a social worker or other specialists. You’ll receive comprehensive care in one setting and may participate in research that will benefit future cancer patients.

MAKE AN APPOINTMENT WITH ORGANIZATION

Whether you go to a late effects clinic or your primary physician, be sure your doctor is aware of your cancer history. Your physician should be assessing your current health status, tracking your progress on previously identified problems, as well as screening you for new problems.

When making medical appointments, keep these things in mind:

- 1) **Share all your medical history.** Any new doctor or medical provider will need copies of your records.
- 2) **Ask questions.** Express any concerns you have about potential late effects of treatments.
- 3) **Discuss any physical changes.** Share your concerns, no matter how small.



- 4) **Schedule yearly check-ups.** Physical exams should include blood count, urinalysis and any other relevant exams.
- 5) **Screen for other cancers.** These include cancers of the breast, cervix and colorectal as recommended by your doctor.
- 6) **Monitor for conditions related to your treatment.** Watch for symptoms or problems. Upon review, your doctor may recommend additional testing.

TOOLS FOR SURVIVAL

Keeping teen and young adult survivors informed is a role we take very seriously. On the NCCS website, theNCCS.org, you'll find our Late Effects After Treatment Tool (LEATT) which allows you and other survivors to develop a risk profile based on the treatment you received. This interactive tool provides results listing the potential medical issues you may face and offers strategies for maintaining your overall health.

By creating a risk profile, you will have additional information to discuss with your physician. If you are not attending a late effects clinic, be sure your doctor is aware of your cancer and the Long-term Follow-Up Guidelines created by the Children's Oncology Group at survivorshipguidelines.org.



"When I transitioned from active treatment, I became a patient in the survivorship clinic where the late effects of my therapy are monitored. At one of my appointments, we learned that my protocol had changed in order to reduce the toxicity of treatment. My doctors, nurses and researchers are all working together to achieve this progress."

Andrew, Leukemia Survivor

"Even though I was very young, I still remember going through chemotherapy, dealing with its side effects, getting shots and blood work done every week, and having to take "thousands" of pills. While some people might focus on this side of cancer as what impacts them most, I like to focus on the good things that impacted my life through Leukemia."

Ben, Leukemia Survivor

THE REAL WEIGHT OF AN OUNCE OF PREVENTION

Along with your annual physical examinations, you should practice preventive medicine. Get regular dental exams and follow-up on any tests that are relevant to your diagnosis. This can vary from person to person. For example, if you had long-term steroid use or radiation delivered around your eyes, you may need regular eye exams to test for cataracts. Certain medications and chemotherapy drugs can have late effects as well. Stay proactive with your health and stay in communication with your doctor to reduce your long-term risks.

FROM CHILDHOOD CANCER SURVIVOR TO ADULTHOOD

Part of becoming a responsible adult survivor entails learning to take control of your own health. As you move away from the oncology setting, you'll find that many doctors aren't aware of all the potential late effects of childhood cancer or what follow-up care is necessary. You will need to become your own advocate. Sometimes, new healthcare providers will need to be educated.



To ease the transition to an adult care setting, it helps to begin initiating more healthcare responsibilities at home. Track your own medical information in a journal. Maintain a thorough treatment summary so you will have accurate details. Take charge of making and keeping your own medical appointments. Keep track of your medications and when you need to order medical supplies. The more responsibility you take, the more empowered you will feel about your own health.

As a young adult, think about the obstacles that may prevent you from attending follow-up appointments. Are you afraid of a recurrence? Do you want to put the cancer treatment behind you? Get in touch with the feelings behind these obstacles and discuss them with your healthcare provider, your social worker or family.

TREATMENT ENDS, QUESTIONS BEGIN

The end of your cancer treatment is a celebrated time, but it's also common to feel some apprehension and confusion. Finding answers to the following questions will help you maintain your long-term health.

- When should check-ups occur and how often?
- What tests are required at follow-up visits?
- What is your doctor's experience with long-term cancer survivors?
- Is there a long-term follow-up clinic you can attend?
- What are the signs of a relapse or a second cancer?
- What are the potential late effects from the treatment you received?
- What are the current recommendations or tests for your particular type of cancer?
- What are the symptoms of potential late effects?
- Is there a special diet you should be following?
- Are there special tests to check your heart, lungs, eyes, teeth, bones and hormones?
- How and when can you reach your healthcare provider with questions?
- Who should you contact with questions related to fertility, activity, psychosocial issues, or concerns about school and/or your job?

FINDING AND PAYING FOR CARE

One of the biggest responsibilities you'll face in an adult healthcare setting is locating and paying for your healthcare services. Services may not be easily accessible and you will have to advocate for your healthcare needs. These suggestions will help you find the best medical treatment available.

- 1) **Look for a long-term follow-up clinic in your area.** Find a list of clinics at theNCCS.org.
- 2) **Find a primary care physician to meet your everyday needs.** Look for a doctor with knowledge of the late effects from the treatment of childhood cancer. Ask your oncologist for a recommendation. Be aware that some primary care doctors will need to be educated on these issues.
- 3) **Understand your insurance coverage.** Discuss your coverage and healthcare financing with your parents before leaving home. You can also discuss your coverage with your health care provider. Whatever you do, don't let your policy lapse.

Transitioning into adulthood is tough for everyone. As a cancer survivor, you face more issues in maintaining your health. Your best tools are your own persistence and determination. Being well-educated and using your own initiative to overcome any healthcare barriers will help you maintain good health and peace of mind.



CHANGE YOUR LIFESTYLE, CHANGE YOUR RISKS

As a survivor, lifestyle can play an important role in your long-term health. Some cancer diagnoses and treatments carry a greater risk of developing certain diseases later in life. Practicing good health habits can reduce these risks and also lessen some late effects. While some risks are beyond your control, there are a lot of lifestyle changes you can make that promote better overall health.

It's important to arm yourself against the late effects that may occur after treatment. The best thing you can do for your health now is to make good choices. Avoid risky behavior and surround yourself with the people who share your values and make smart choices for healthy living.

SMOKING KILLS

Tobacco use and smoking is the single most preventable cause of death in the United States. Statistics show that one million teens will start smoking each year and one-third will eventually die from their addiction. Electronic cigarettes or vaping may seem like a safe alternative, but research shows that e-cigarettes contain highly addictive nicotine and potentially toxic chemicals not yet understood. The best thing you can do to maintain your health is to never smoke, use any form of smokeless tobacco, or electronic cigarettes. If you currently do, make a pledge to quit.

Stay away from second-hand smoke, too. Non-smokers who live or work with smokers experience a 30-50% greater risk for lung cancer. That makes second-hand smoke the number one preventable risk factor for serious and chronic diseases of non-smokers in our country. Avoid exposure to tobacco whenever you can.

Tobacco is highly addictive, so quitting is difficult. But studies show that smokers who quit before age 50 will cut their risk of dying in half over the next five years. If you have trouble quitting, get help. To learn more about quitting smoking, call the Center for Disease Control and Prevention at 800-232-4636 or the National Cancer Institute at 800-4-CANCER.

THERE'S NOTHING WRONG WITH EATING RIGHT

What you eat has a direct impact on your health. Although childhood cancer isn't directly related to diet, eating a balanced diet is key to any healthy lifestyle. A policy study from the American Institute of Cancer Research reports that of the 12 common adult cancers, about 35% of cases in the USA are preventable through a healthy diet, being physically active and maintaining a healthy weight. A healthy diet should include a variety of fruits, vegetables, nuts and beans. Limit your intake of red meat and processed foods that are high in sugar, low in fiber or high in fat. Watch the salty foods, too, and cut back on processed foods high in salt.

Keep an eye on portion sizes. Make your food portions in line with standard serving sizes. Two-thirds of your diet should be plant-based foods, while one-third or less should come from meats and cheeses. Cured meats like bacon and cold cuts should be eaten on rare occasions. Be creative with your diet and shoot for variety in what you eat. And always talk to your doctor before making any dietary changes.



TIPS TO EAT BY

Maintaining a healthy diet can be overwhelming at first. But these simple tips will help you ensure the foods you put in your body will do right by you.

- 1) **Limit your salt intake.** Use other herbs and spices like paprika, garlic powder, thyme and oregano to flavor food. High salt intake may contribute to high blood pressure in some people.
- 2) **Stay away from fat.** Only 20-25% of your total calories each day should come from fat. Less than one-third of these calories from fat should be from an animal source.
- 3) **Avoid fast food.** It's high in fat, calories and sodium.
- 4) **Drink skim milk.** Substitute whole milk with fat free, Vitamin D fortified milk.
- 5) **Use low-fat varieties of dairy products.** Eat only moderate amounts of cheese.
- 6) **Skip the butter.** Opt for olive oil and canola oil in cooking.
- 7) **Eat enough protein.** As you eat less meat, add other protein sources such as soy products and beans.
- 8) **Monitor your health with your doctor.** Discuss any changes in your weight, appetite, or problems with digestion. Ask if there are specific nutritional needs related to your diagnosis or treatment.
- 9) **Don't be misled by restaurant portion sizes.** Servings are much larger than one person needs, so don't eat everything on your plate. Take leftovers home.

MOVE IT ALONG, FOLKS

Exercise provides great physical and mental benefits for the body. Regular physical activity has been proven to reduce the incidence of colorectal cancer, coronary disease, osteoporosis, diabetes and possibly breast cancer. Exercise also improves mood, boosts self-esteem, stimulates the immune system, and reduces the symptoms of pain, diarrhea and constipation.

Start a workout plan that has a consistent level of limited to moderate activity and do it several times a week. USDA guidelines recommend that adults should have 60 minutes of moderate to vigorous activity, most days of the week. Moderate activity is considered exercise that raises your heart rate.

Diet and physical activity together will help you maintain a healthy weight that your doctor defines as normal for your height. Research shows there is an increased risk of obesity with certain types of childhood cancer. Think of weight as a long-term health goal. Once you reach your optimum weight, limit weight gain throughout adulthood to less than 11 pounds. Avoid frequent weight fluctuations. The American Institute for Cancer Research offers great nutritional guidelines for maintaining a healthy weight on their website at aicr.org.

Even if you're in good health and feeling great, talk to your doctor before beginning any workout program. Certain chemotherapies used in treating childhood cancer can lead to increased risk of heart disease, so your doctor will need to be aware of your activity level to assess your risk.

Remember, you can build your own late effects assessment at theNCCS.org to proactively care for yourself as a survivor.

A TOAST TO BEING ALCOHOL FREE

As you begin mapping out your way to healthy living, you're bound to run into some challenges. Alcohol may be one of them. Alcohol provides a lot of calories without any nutrition. Evidence also suggests that drinking large amounts of alcohol increases your risk of several types of cancer and other chronic conditions. It's easy to see why drinking isn't recommended as part of a healthy lifestyle.

HEALTHY LIVING



The legal drinking age is 21, yet a staggering 70% of American high school seniors have consumed some form of alcohol within the last month. Studies show that the sooner a person starts drinking, the more likely they are to have alcohol-related problems in adulthood.

If you are of legal drinking age and choose to drink, do it in moderation. Don't justify a night of heavy drinking by not drinking alcohol several days in advance. In fact, many studies show that binge drinking is more dangerous than moderate alcohol consumption. Part of being a responsible survivor is making healthy choices about everything you put in your body.



"Because of those possible side-effects, I try to live as healthy a lifestyle as possible. I pay more attention to what I put in my body and how I treat it, and try to exercise as much as I can."

Ashley, Leukemia Survivor

"It helps to surround yourself with the right people, especially when it comes to smoking and drinking. If alcohol and cigarettes are around you, it's more likely to be a problem."

Phillip, Ewing's Sarcoma Survivor

FIND YOUR SAFE PLACE IN THE SUN

We all enjoy a little sunshine, but too much sun exposure can cause serious health problems.

Melanoma is a serious form of skin cancer, and it's the most common form of cancer in Americans aged 25-29. Everyone experiences some burning and damage from the sun, but taking these preventive steps will help you minimize further skin damage.

- 1) **Use a minimum of SPF 30.** Apply 15-20 minutes before sun exposure. Broad spectrum SPF 30 will block out 97% of UV rays, which are the more dangerous burning rays.
- 2) **Apply sunscreen every two hours.** Apply a thick layer and reapply after swimming.
- 3) **Check the date on the package.** Sunscreen has a shelf life of two years.
- 4) **Limit your time in the sun.** Avoid peak hours of damaging rays between late morning and early afternoon.
- 5) **Shade yourself in peak hours.** Wear a hat with a wide brim or carry an umbrella to create extra shade.
- 6) **Wear sunglasses.** Protect your eyes from exposure to UV light.
- 7) **Avoid reflective surfaces.** Water, sand and concrete can increase your risk of burning rays.
- 8) **Don't use indoor tanning beds.** They contain the same dangerous UV rays as natural sun exposure.

Keep an eye out for changes in moles on your body. While most moles are harmless, alert your doctor if any moles change color, shape or size, or suddenly appear out of nowhere. Pay attention to moles with irregular borders or any moles that bleed or are itchy. A change of a couple millimeters in a single mole can actually make the difference between life and death.

If you have already been exposed to radiation treatment, you are at a higher risk for skin cancer and should limit your sun exposure as much as possible. Be sure to keep an eye on moles in areas of your body that have received radiation therapy. You can't ever be too careful with skin cancer.

EMOTIONAL CHALLENGES



HEALING YOUR MIND AS WELL AS YOUR BODY

It's easy to understand the physical healing that you must endure with a cancer diagnosis. But childhood cancer affects you emotionally, too. Throughout your life, you may experience heightened feelings, both positive and negative. Often, you'll be able to incorporate these feelings into your life and hopefully draw courage and inspiration from them.

EVEN EMOTIONS HAVE GROWING PAINS

Some survivors experience post-traumatic growth, (Tedeschi and Calhoun, 2004) which can be expressed in many different ways. You may gain a greater appreciation for life and every new experience. Cancer can give many people personal strength, spiritual development and better interpersonal relationships. Facing your fears and triumphing is what being a survivor is all about.

Experiencing post-traumatic growth doesn't mean you have overcome the stress of your cancer experience. Surviving your diagnosis and treatment at a young age brings with it a roller coaster of emotions. Many survivors experience depression, anxiety and fear. And long after the end of treatment, some survivors experience post-traumatic stress.

When times get tough, it's important to learn how to handle stress and emotional challenges that come with your diagnosis. Good coping skills can help you integrate the cancer experience into your life, instead of being ruled by it.

HOLDING ON AS THE RIDE GETS BUMPY

The end of treatment is indeed a joyous time. Certainly, it is a cause for celebration, but you may also begin to feel anxious. Losing constant contact with your healthcare team may be frightening. Friends and family who provided support during your treatment may not understand that cancer is still part of your life. It's easy to feel alone.

You may also fear potential late effects, a relapse or have some physical changes that are causing anxiety. Sometimes, survivors experience greater anxiety because it is finally safe to allow yourself to feel everything you held back during treatment.

Feelings of stress and anxiety are common. Finding ways to cope and relieve these feelings will help you maintain a healthier lifestyle.

- 1) **Move your body.** Exercise at least 30 minutes, four times a week with your doctor's approval.
- 2) **Eat healthy.** The good foods you put in your body will have a positive impact on your emotions and your physical health.
- 3) **Avoid alcohol and drugs.** These can mask your true feelings and cause other health complications.
- 4) **Avoid stimulants.** Caffeine and decongestants can interfere with your sleep.
- 5) **Get lots of sleep.** Get at least eight hours a day.
- 6) **Start a hobby.** Find something you like to do alone, such as knitting or painting. Or, involve others by joining a book club or sports team.

EMOTIONAL CHALLENGES



- 7) **Talk about your concerns.** Join a support group or discuss things with a friend, counselor or clergy member.
- 8) **Learn to pace yourself.** Set priorities for yourself that include making time for activities that you like to do.
- 9) **Relax.** Learn techniques such as deep breathing or meditation that will allow you to unwind when you're feeling tense.

Fear of recurrence is very real and can be intense for many survivors. When these fears take over, take a moment to determine your actual risk of recurrence. Think how you can be proactive about reducing your risk of the cancer returning. Have your potential problems evaluated by a medical professional. And always talk with someone about your concerns. Don't leave things bottled up. Whatever you do, don't let these fears keep you from living a happy and healthy life.

WHEN THE BAD FEELINGS DON'T GET BETTER

At the anniversary of your diagnosis, you may find that you experience disappointment, tiredness and loneliness. Lots of survivors have these feelings. It's important that you learn to distinguish between "normal" levels of sadness and a more serious case of depression. Symptoms of depression include loss of interest in most activities; changes in eating and sleeping habits; nervousness; tiredness; sluggishness; worthlessness; poor concentration; too much sleep or difficulty sleeping at all.

It is common for survivors to experience these symptoms in the years following cancer treatment. Generally, they lessen with time. If you have feelings that persist or they are beginning to affect your relationships or your ability to work, seek help. Don't hesitate to use these resources to get the guidance you need.

-psychologytoday.com

-The National Suicide Prevention hotline: 800-273-8255

-911

POST TRAUMATIC STRESS AFTER CANCER

Survivors who are treated at a young age may not be fully aware of how their cancer experience has affected them. Some choose to ignore their feelings and just move on with life. Studies show that unresolved feelings of helplessness and anxiety may increase the risk of post-traumatic stress disorder (PTSD).

Symptoms of PTSD include:

- Recurring and distressing dreams or recollections about the event
- Inability to recall important aspects of the trauma
- Heightened arousal, such as nausea or increased heart rate, which is triggered by reminders of the original experience
- Feelings of detachment from others
- Sleep disturbances
- Irritability or outbursts of anger

EMOTIONAL CHALLENGES



- Difficulty concentrating
- Intrusive, unwanted thoughts
- Avoidance of stress-inducing settings and situations

If you are worried that you are experiencing PTSD, contact a professional counselor or one of your hospital social workers. For a list of specialists and support groups in your area, contact the American Cancer Society at 800-ACS-2345 or Cancer Care at 800-813-HOPE.



"I have found that my willingness to be open and honest about what I have experienced encourages others and continues to open up more doors of opportunity. If I had bottled it up and never wished to talk about cancer, I would have missed out on so many wonderful experiences."

Cole, Lymphoma Survivor

"Sometimes, the fear takes over, especially around the anniversary of my diagnosis or when I have to get annual testing. But I know I'm strong. I remind myself that I have overcome cancer once and I can do it again if I need to."

Maggie, Hodgkin's Lymphoma Survivor

REACHING OUT FOR SUPPORT

Connect with other parents who have a child with cancer at the NCCS' private Facebook support group: facebook.com/groups/childhoodcancersupportnccs. Connecting with people who have shared similar cancer experiences and emotions can be helpful in the healing process. A childhood cancer support group is a great place to talk about your fears and emotions. Survivors share information, provide emotional support and inspiration to boost one another's sense of self-worth. Sometimes, sharing your experience makes you feel like you're helping others which gives you a chance to grow and heal.

Is a support group a good option for you? You'll need to be comfortable sharing your feelings, be interested in learning about others' experiences, and enjoy being part of a group dynamic. The setting gives you a platform to provide helpful information to others and to reach out to other survivors in need of emotional healing. Every support group has a unique make-up and the focus of the meetings can be different from one week to the next depending on who attends. Be sure to attend a group at least twice before deciding whether or not to join.

Online support groups are another way to go. You can talk about your feelings and concerns and still maintain a feeling of anonymity. Connect with other parents who have a child with cancer at NCCS' private Facebook support group: facebook.com/groups/childhoodcancersupportnccs.

Support is where you find it. If you're not comfortable in a group setting, reach out to a psychologist, social worker, psychiatrist or clergy member. Talk to your family and friends and explain how they can help you. Or, extend your support to others. It can relieve your isolation and allow you to feel empowered and more in control. More than anything, draw on your own strengths. Read books by other survivors and reach inside to find the strength and support that got you through this incredible journey.



MAKING SENSE OF ALL YOU'VE LOST

Young Adult Survivor. Sounds like a TV reality show, doesn't it? You know more than anyone, being a cancer survivor couldn't be more different than TV. You didn't choose this role, and you can't just walk away. But you are in fact a young adult cancer survivor.

Thankfully, you didn't die, though you probably had friends who did. But you have paid a price for your survival and lost a lot along the way. You may have missed out on the chance to play sports, attend prom or participate in clubs. Maybe you missed getting the grades you hoped for, graduating on time (if at all), college scholarships or even working part-time.

Childhood cancer survivors experience a great deal of grief from the losses they face. You don't have the freedom to go places without your parents worrying. You may feel alienated from your peers due to your shifting values and priorities.

WHERE DID MY CHILDHOOD GO?

Cancer takes certain things from you. You may no longer have the confidence to envision your life as a grown-up. Physical losses like an eye, a limb or the ability to have children may be part of your new normal. Or perhaps you've lost academic or physical abilities you once had, changing your image of yourself. What you've lost is part of your childhood.

More than anything, it can feel like you've lost yourself. You're bound to have questions about the hand you were dealt. Why did this happen to me? Why did I survive and my friend didn't? What kind of future can I have now? How do I hold onto my beliefs after all I've seen and been through?

GRIEF HAS NO EASY ANSWERS

Quite often, the questions that arise after a life experience like childhood cancer have no easy answers. They may force you to reevaluate your relationships, your goals, your faith and your outlook on the future. Only let it take what it must and what you don't want anyway.

These losses inevitably result in grief. All cancer survivors experience some levels of grief; you don't have a choice. How you deal with your grief, however, is a choice. Ignoring the realities of your situation won't help you move beyond them. The goal is to find ways to keep the mourning you're experiencing from causing more losses in your life.

Unlike your cancer treatments, there is no radiation or chemotherapy for grief, but there are ways to keep it from spreading and damaging you. Talk to others, write about your feelings, seek professional help, or pray. If it helps, allow yourself to cry and feel the pain. Identify the things you've lost and what you haven't. Some people feel that digging into work, finding a new project or setting new goals gives them ways to move forward.

WAYS TO COPE

Different strategies for dealing with grief work for different people. These are some coping mechanisms that many survivors use.

- 1) **Denial.** Denial is when something doesn't feel real or cannot be accepted. Feeling this way, especially in the beginning, is fine. Denial helps us gradually get used to the reality of the loss.



- 2) **Distraction.** Thinking about grief all the time doesn't help anyone. Part of coping is doing the things that take your mind off of the grief. Even when you don't feel like it, doing things to distract you can be helpful.
- 3) **Deal with the grief.** Trying to bury your feelings before they are ready to leave just doesn't work. Feelings of grief are strong and will continually return. Let yourself express the grief in a way that makes you more comfortable. Talk, write or think. Consider doing something in memory of someone; plant a tree, write a poem or even gather friends to reminisce.

"Those who were not as lucky as I was will live on in me and their lives will have greater meaning. Fighting cancer is a tough battle, but once the victory bell is rung, every survivor becomes a champion in their own right."

Phillip, Ewing's Sarcoma Survivor

"Sometimes, surviving when others don't can cause a lot of internal stress. There's a feeling of needing to live your life to the absolute fullest to honor them."

Jenna, Lymphoma Survivor

"If we live closed off from the world, we may never experience grief or pain. But we also miss out on love and joy. When we feel grief, we are open and vulnerable, and can therefore experience the fullness of life."

Phillip, Ewing's Sarcoma Survivor



FINDING STRENGTH IN WHAT YOU LOST

It may be hard to understand, but many losses can lead to significant gains. This idea is demonstrated well in the book "Harry Potter and the Order of the Phoenix." As the story begins, Harry is grieving, angry and upset about the death and loss of a trusted friend.

But as the story unfolds, Harry's experience with death gives him new powers. Before his friend's death, Harry thought that the students' carriages were pulled to school by magic. Now, Harry can see that they are pulled by thestrals-fierce, meat-eating horse-like creatures that are invisible to most of Harry's friends. He soon learns that only those who have seen death can see thestrals. Later in the story, Harry uses this knowledge in a successful heroic quest. If his friend had not died, Harry would not understand these creatures. His quest inevitably succeeds because of the powers Harry gained in the losses he experienced.

The losses of childhood cancer can lead to some hard-won gains as well. Some survivors find maturity, wisdom and perspective beyond their years. This deepened perspective and wisdom, when compared to the host of losses young survivors experience, may hardly seem like an even trade. But the gains are real nevertheless.

(The content of this article was contributed in part by Greg Adams, LCSW, ACSW, CT-Director, Center for Good Mourning, Arkansas Children's Hospital.)

RELATIONSHIPS



MAKING AND RE-ESTABLISHING HEALTHY CONNECTIONS

After your cancer experience, you may at times feel different from your peers. Many survivors gain a tremendous amount of maturity and empathy for others. Some realize that their concerns, interests or values have changed. As a result, it can make you feel disconnected from others your age.

Surviving cancer gives you strength, self-confidence and allows you to take a more open approach to life. Your peers may see you as a role model and your experiences may help them find a new perspective in their own lives.

FRIENDSHIPS CHANGE

You may find that your cancer experiences change some of your friendships. During treatment, you often meet new friends. You may not feel as close with some friends as you once did. And unfortunately, you may lose some friends. This can happen for many reasons. In high school, these things happen even without cancer.

SHIFTS IN FAMILY DYNAMICS

A cancer diagnosis often causes roles and responsibilities to change within a family. Parents become more protective of a child with cancer and the experience may make you more dependent on them. Once treatment ends, you may expect your parents to jump back to their old roles while you return to being more independent.

Your parents may have ongoing worries that make them uncomfortable with your need for independence. This is all normal. Talk openly with them about your concerns and listen to theirs. Some of their fears may seem irrational, but try to remember—cancer affected your whole family. Showing them maturity, self-esteem, confidence and good decision-making will slowly ease their worries.

Cancer may have a completely different meaning to you than your parents. You may both feel some anxiety at the end of treatment as you begin separating from your medical team. Remember, it is difficult for them, too. You may have to remind them that although cancer is still part of your life, you will need to establish your own support system outside of the cancer community. It doesn't mean you are breaking all ties. You are choosing a new role for cancer to play in your future and this is to be celebrated.

RELATIONSHIPS



KEEP THE LINES OPEN

There are ways you and your parents can work together to understand each other's feelings. Discuss your cancer memories. Talk openly about your diagnosis and treatment and how it will affect your future. Or, talk to your social worker to learn ways that other survivors dealt with finding independence after treatment.



"I remember a time in gym class when we were learning to square dance and a boy refused to hold my hand because he said I had a disease. I was rejected by my classmates based on something I had no control over. By possessing this "outsider" status at such a young age, I was able to learn valuable lessons about friendships and how to overcome issues like this in the future.

Sarah, Leukemia Survivor

"I definitely fought with my parents more during treatment. I know they were protecting me, but it was hard because I still wanted to be a high school student."

Phillip, Ewing's Sarcoma Survivor

Don't be surprised if you find yourself having the same discussions with your siblings. Cancer affects the entire family, so your siblings will probably experience a wide range of conflicting emotions about your diagnosis and treatment. They may feel empathy, increased closeness and protectiveness. But they may also feel jealousy, guilt, fear, anger and neglect. Remember, they need you. Show openness and concern. It will help them resolve these feelings. Cancer can make sibling relationships stronger than ever.

OPENING YOURSELF UP TO DATING AND MARRIAGE

The time from adolescence to young adulthood is tough for everyone. Even without the complications of something like cancer, young people often struggle with self-esteem and worry how they will compare with others. This is a time of increased sexual interest- making teens and young adults more focused on appearance and body image.

Needless to say, this period can be especially rough for survivors. Cancer treatments may have changed the way you look. You may have lost or gained weight, have surgical scars or other changes in your physical appearance that have affected your self-esteem. These things can make you uncomfortable about pursuing a relationship.

WORK ON YOUR RELATIONSHIP WITH YOURSELF

The key to forming healthy and productive dating relationships is to strengthen your self-esteem. It's hard to care for someone else until you are confident in your own skin. These ideas will help you to create a more positive self-image.

- 1) **Exercise.** It releases endorphins which lead to positive feelings.
- 2) **Don't compare yourself to others.** There's only one you and no one else has had the same experiences as you.

RELATIONSHIPS



- 3) **Find your special skills.** Whether it's writing, dancing, singing, video games, sports or academic interests, learn what makes you happy. Then do it!
- 4) **Say positive things about yourself.** Talk to yourself in ways that help boost your self-esteem.
- 5) **Surround yourself with positive people.** Optimism is contagious!
- 6) **Make a list of past successes.** Reward yourself for your accomplishments.
- 7) **Set future goals.** Make a plan for how you will achieve them.
- 8) **Learn to laugh at yourself.** A good sense of humor and the ability to laugh at yourself will increase your enjoyment of life.

A TIME FOR INTIMACY

Sexual intimacy occurs at different times for different people. Mostly, it occurs within the confines of a committed relationship. As a survivor, you must assume and act like you can become pregnant unless you are absolutely certain you cannot. You should always practice safe sex to reduce your risk of sexually transmitted diseases.

When you are in an intimate relationship, you may experience concerns about your sexuality. These may include fertility issues or worries about your health. Depression, guilt, fear or fatigue may affect your ability to perform sexually. Low self-esteem can also make you desire sex less frequently. Some survivors also have anxiety about sex or have difficulty becoming aroused or finding pleasure in sex. Others avoid sex altogether or engage in it too frequently or dangerously.

Sexuality brings with it a slew of confusing feelings. The key to overcoming these feelings is to be honest with your partner, as well as your doctor. Discussing reproductive issues and sexual concerns can be embarrassing and scary. Thankfully, the benefits of an open discussion far outweigh keeping these concerns to yourself. By discussing these issues and working to feel better about yourself, you will develop happier and healthier relationships.

SEEKING HELP ALONG THE WAY

It's important to be well informed about possible sexual and/or fertility problems and to be willing to talk about these concerns with your partner, your doctor, and if you choose, a professional counselor. If you need additional help related to sexual issues, you can get referrals to a licensed sex therapist or counselor through the American Association of Sex Educators, Counselors and Therapists. To learn more, visit aasect.org.

The success rate of marriage is the same for cancer survivors as it is for the general public. Intimate relationships require work and it can be difficult at times. But openly addressing these issues and focusing on having positive self-esteem will help you build your confidence and strengthen the relationships that matter to you most.



CONCEIVING ALL THE POSSIBILITIES

Fertility can be a sensitive and deeply emotional topic for cancer survivors. Some cancer treatments cause fertility problems in both men and women. Thankfully, modern medicine continues to make advancements in treating infertility, as well as in minimizing the late effects of treatment related to fertility. The Livestrong organization helps patients faced with infertility. For more details about the program, visit Livestrong.org.

WHAT IS INFERTILITY?

Infertility is defined as the inability to start or maintain a pregnancy. Some cancer treatments, such as radiation to the testes or the ovaries, or alkylator drugs can cause a person to become infertile. These treatments can also make it more difficult to conceive and/or maintain a pregnancy. Other factors that may affect a childhood cancer survivor's fertility rate include:

- Type and location of cancer
- Age and developmental age at time of diagnosis
- Gender
- Types of chemotherapy received and dosage
- Area and amount of radiation received
- Type of surgical procedure

As a young adult survivor, you may not yet know the real impact your treatment has had on your fertility. It's important to discuss questions with your parents or someone on your healthcare team to get honest and accurate information. Talk about the type of cancer and treatment you received to get a more complete picture of your risks.

Keep in mind, information is continually being updated. Some treatments that were thought to cause infertility may no longer have the same affect and the body has been known to do miraculous things. World renowned athlete and cancer survivor Lance Armstrong was able to conceive naturally, when most people who receive the same treatment may be left infertile.

Knowing all the facts may impact your decisions about using birth control, so consider consulting with an infertility specialist. As a responsible young adult, you should assume and act as if you can become pregnant unless you are absolutely sure you cannot. And always, practice safe sex to reduce your risk of sexually-transmitted diseases.



EXPLORING YOUR OPTIONS FOR STARTING A FAMILY

If you reach the point in life where you are considering starting a family, rest assured, you will have options. If you are infertile and would like to have a child, you can explore fertility cycle enhancement, donor insemination or donor eggs. In vitro fertilization and surrogacy are other reliable parenthood options.

Some choose to forego treatments and adopt. Others consider independent adoption, international or foster-care adoption, while others decide to remain childless. If you have accepted infertility and found other ways to be fulfilled in life, it can be a rewarding choice. You may consider including children in your life by volunteering at a school, camp or non-profit organization. Take an active role in the lives of children who are close to you, such as nieces, nephews or the children of friends.

IS INFERTILITY COVERED BY MY INSURANCE?

How much of your infertility treatments that are covered by insurance will depend on where you live and the type of plan that you have. Some states have laws that require insurers to offer some form of infertility diagnosis and treatment. Laws can vary greatly in their scope and depth of coverage.

To learn more about the specific laws in your state, visit your state's insurance commissioner's office. For pending insurance legislation, contact your state representative. Whether or not you live in a state with infertility insurance laws, talk with your employer's human resources department to better understand the coverage your plan provides. To check on current healthcare reform or how it may impact infertility treatment, visit healthcare.gov.

MAKING SENSE OF INFERTILITY

Dealing with the overwhelming medical decisions and uncertainties of infertility can take a toll. The long-term inability to conceive can bring on a significant feeling of loss. It can leave one feeling anxious, depressed, out of control and isolated from the world around them. If you find yourself with persistent feelings like this, please seek professional help.

During infertility treatment, you may reach a crossroad. You may need to decide between different treatment possibilities, to consider using a third-party for assistance or to explore all your options for building a family. At times like these, it's not uncommon for couples to have difficulty communicating with each other about the different directions to take. Discussing your options, as well as your feelings, with a mental health professional can clarify things and help you make more informed decisions.

For guidance in managing infertility, visit resolve.org.



WHEN THE GRIEF DOESN'T GET BETTER

When you are pursuing infertility treatment, it's normal to experience ups and downs, or to feel overwhelmed. If these feelings last over a prolonged period of time, it may help you to work with a mental health professional. The following symptoms may indicate you need counseling to deal with the grief associated with your loss.

- 1) **Depression won't go away.** You are uninterested in your usual activities and the sad mood won't lift.
- 2) **Relationships are strained.** You feel socially isolated and have trouble being around people.
- 3) **You can't think about anything else.** You have difficulty concentrating and accomplishing even simple tasks.
- 4) **Appetite and sleep patterns change.** You experience weight gain or loss; you may sleep constantly or sometimes not at all.
- 5) **You use alcohol or drugs to cope.** You find yourself drinking more or using drugs frequently to deal with your feelings.
- 6) **Thoughts are very dark.** You experience persistent feelings of guilt, worthlessness, bitterness and anger. Thoughts sometimes turn to death and suicide.

"One late effect is hard for me to accept: I know I'm not going to be able to have kids. I have to come to terms with that. I try to find the optimistic side – I'm going to adopt. Maybe I was meant to save kids, not have them."

Lindsey, Hodgkin's Lymphoma Survivor

"When I look at my body now, I can't help but think about my cancer. In place of my right ovary and a healthy cervix are dark, visually unpleasant scars. These symbols of my developing womanhood have been replaced with incessant worry over how to go on with the rest of my life without allowing my past to consume every future thought and action."

Amanda, Ovarian Cancer Survivor



TO GROW, TO SUPPORT, AND TO COPE

There are mental health professionals who specialize in counseling people undergoing infertility treatment. Receiving psychological counseling can give individuals and couples a great deal of support, teach them to cope with the physical and emotional changes that come with infertility, and suggest ways to best manage the often painful and intrusive medical treatments.

For some, the focus may be on how to deal with their partner's response. For others, it may be about choosing the medical treatment that's right for them, or how to explore other family building options. Some may need help learning to control their stress, anxiety or depression.

Counselors teach problem-solving strategies in a supportive environment to help people work through their grief, fear, and emotions. The ultimate goal is to reach some kind of resolution with infertility. A good therapist can help you sort out these feelings, strengthen coping skills and give you the tools to better communicate with others. In the end, the life crisis of infertility can prove to be an opportunity for life-enhancing personal growth.

For guidance in managing infertility visit: Resolve.org.



ISSUES RELATED TO YOUR COVERAGE

Everyone needs dependable health insurance coverage, but it's especially important for cancer survivors. It's also critical that you thoroughly understand your policy and know your rights.

If you're a teen, you are probably still under your parent's coverage so you might not feel pressured to understand the information on your policy. Before heading off to college or pursuing a new career though, you will need to know where your coverage stands, how it works, and begin taking over some of the responsibilities for it.

A LAPSE IN COVERAGE IS A LAPSE IN GOOD JUDGMENT

It is extremely important that you maintain continuous health insurance coverage at all times. No exceptions. Be sure to discuss your plan with your parents. As a cancer survivor, you may have trouble getting new coverage if your policy lapses. If you are self-employed or unemployed and seeking private coverage, you may face high premiums and have pre-existing conditions related to your cancer waived or excluded from coverage. You may also experience an extended waiting period, depending on your insurance plan.

Understanding your health insurance coverage can be overwhelming, but take heart. Currently, under federal law, you cannot be denied coverage for your illness or related health problems by any insurer if you don't have a lapse in coverage.

UNDERSTANDING YOUR HEALTH INSURANCE OPTIONS

Insurance policies and legal issues are confusing and complex. Here are some guidelines to help you navigate.

Managed Care

Most employer-provided health insurance is a form of managed care. This model provides health-care services in the most cost-effective manner. There are several common types of managed care. These include Preferred Provider Organizations (**PPO**), Point of Service Plans (**POS**), Health Maintenance Organizations (**HMO**), and Health Savings Accounts (**HSA**). Your employer's human resources manager can help you better understand which type of policy coverage you have.

Group Insurance

If your employer does not offer healthcare coverage or you are self-employed, investigate group healthcare policies. Be sure to check any carrier with your state's department of insurance, which regulates plans and companies, before purchasing a policy. As with any industry, you should be wary of fraudulent insurance providers.



Health Insurance Marketplace

The marketplace provides online information about insurance options and allows individuals to purchase health insurance. Most states utilize the federally facilitated marketplace, but others operate state-based marketplaces. You can compare plan options and costs to decide what option is best for you. There is an open enrollment period for eligible individuals. For more information or to review your options, visit [healthcare.gov](https://www.healthcare.gov).

State and Federal Programs

You may also qualify for state or federal health insurance. **Medicaid** and **State Children's Health Insurance Programs (S-CHIP)** are two government sponsored programs you may qualify for. Currently, state and federal laws offer cancer survivors very limited help in obtaining health insurance, but advocates are working to improve this situation.

Drug Coverage Programs

The NCCS offers a discount prescription drug card program. The NCCS card is available at medical clinics, hospitals and pharmacies nationwide for individuals with limited or no prescription drug coverage. Not only does using the card provide you significant savings, it also generates contributions to the NCCS. Visit theNCCS.org/agelity to print a card and locate participating pharmacies.

Individual Policies

If you haven't been able to obtain health insurance through any of the above options, you may have to purchase an individual policy. These policies can be extremely expensive, but an insurance broker can help you find options. These are some things to consider before purchasing any individual policy.

- 1) **Can your parents extend their policy to cover you?** Sometimes the cost of adding someone to an existing family plan is less than buying individual coverage.
- 2) **Have you contacted your state representative or congressperson?** Most offices have case managers who can advocate for you and answer your questions. For contact information, visit [senate.gov](https://www.senate.gov), [house.gov](https://www.house.gov), or call 202-224-3121.
- 3) **Have you tried the National Association of Insurance Commissioners?** This agency can provide contact information and details of state health insurance programs. Learn more at [naic.org](https://www.naic.org) or call 816-783-8500.

HEALTH INSURANCE



THE LAWS AFFECTING INSURANCE COVERAGE

Employers are not always required to offer health benefits to all employees. If you are offered group health coverage, you have certain rights under federal and state laws. These include:

- 1) **Anti-discrimination.** You cannot be denied coverage based on your past or current state of health.
- 2) **Coverage for pre-existing conditions.** Some group health insurance plans may temporarily exclude a certain health condition. Usually, this cannot last for more than 12 months.
- 3) **COBRA.** The Consolidated Omnibus Reconciliation Act is a federal law allowing you and your dependents to remain in your group plan for up to 18-36 months after employment is terminated. When you accept COBRA coverage, you are typically responsible for paying the entire premium.
- 4) **HIPAA.** The Health Insurance Portability and Accountability Act protects the health coverage of individuals who have a pre-existing health condition. Before this law was passed, individuals with a health condition could be excluded from group health insurance with a new employer.

"Another way my journey continues is in my current health. I have been faced with many long-term effects of my treatments. When I come home from school, I spend at least one day of my break at a doctor's appointment. As a survivor, I know what I am capable of, what I do best, and that is to fight and continue my journey."

Lexi, Ewing's Sarcoma Survivor

"I have cancer check-ups every three months that involve a visit with the oncologist, scans and blood work. Basically, there is A LOT of follow-up care with no end in sight. The copays alone are a burden, so I am very lucky to be on such a good health insurance plan."

Casey, Ewing's Sarcoma Survivor



THE RULES RELATING TO HIPAA

If your employer provides health insurance, these rules will apply relating to HIPAA.

- 1) **HIPAA limits exclusions for pre-existing health conditions.** A pre-existing condition is one for which medical advice, diagnosis or treatment was received or recommended in the six months prior to enrollment in a new health plan.
- 2) **Pregnancy or the health condition of a newborn child is exempt from pre-existing condition exclusions.** Any genetic information, in the absence of a diagnosis, is not treated as a pre-existing condition.
- 3) **The maximum amount of time that pre-existing condition exclusion can apply is 12 months after the enrollment date.**
- 4) **If you were covered by another plan and coverage did not lapse, your new plan must reduce the pre-existing exclusion period by the number of days that you were covered under your old plan.** You will have to provide coverage documentation. If you have been covered by insurance for the past year without a break in coverage, the pre-existing exclusion does not apply.



LEARNING THE INS AND OUTS OF INSURANCE

No matter what the state of your health, it is imperative that you understand your coverage so that you can make the most of your insurance. These are good questions to ask.

- Which doctors and hospitals are included in the provider network?
- What medical services require pre-authorization?
- Does your prescription coverage include name brand or generic drugs? What percentage of the cost does your plan cover?
- What inpatient and outpatient treatments are covered?
- Does your policy have a lifetime maximum cap for treatment?
- Does your insurance cover any ancillary expenses related to medical care, such as lodging, meals or transportation?
- Does your policy require that you pay up front in full for medical care and then you are reimbursed, or are the claims filed by your provider on your behalf?
- Who is your contact person at the insurance company? Whom should you contact regarding denials?

WHAT IF INSURANCE DENIES MY CLAIM?

Sometimes, insurance companies deny a claim. Many times, denials are the result of errors. If you feel you were wrongly denied, you'll want to investigate the decision. It's possible for the doctor's office to have miscoded an item or for a bill to have been filed in an untimely manner. Investigating the matter will hopefully clear things up. You will need to contact the provider's billing office or the insurance company to clarify why the claim was denied. If a mistake is identified and corrected, the insurance company may then be able to reverse the denial and make payment on the claim. Understanding your coverage and tracking your appointments, authorizations, communications, and EOB's may seem overwhelming, but will save you in the long run.

If you receive a denial that isn't the result of a billing error, you may still want to appeal the decision. Make sure you know the insurance company's timeframe for appeals. Listed below are the steps to take for filing an appeal:

- 1) **Obtain a written copy of the denial that lists the reason for the denial.** Denials can occur for a variety of reasons, but are normally a result of what the insurance company does not consider standard of care.
- 2) **Check your insurance guide.** If the guide states the procedure is covered, contact the insurance company to clarify why payment was denied.
- 3) **If denial is based on non-standard care, ask your doctor to write an explanation to the insurance company.** Insurance companies are not always aware of the latest treatment procedures and medical documentation submitted by your physician may aid in reversing the denial. Advocate for yourself and follow-up with the insurance company regarding the status of the appeal.

If your insurance company persists in what you consider to be an unjust denial, consider contacting a third party, such as the Patient Advocate Foundation at 800-532-5274 or your state insurance commissioner.

HEALTH INSURANCE



THE PATIENT PROTECTION AND AFFORDABLE CARE ACT (PPACA)

The Patient Protection and Affordable Care Act (PPACA), was signed into law on March 23, 2010 by President Barack Obama. The healthcare reform law was estimated to provide coverage to more than 30 million Americans who lacked health insurance. Because healthcare legislation seems to change on a regular basis, what is in effect today can be altered or eliminated tomorrow. Stay updated on the latest healthcare developments by visiting healthcare.gov.

EDUCATIONAL CHALLENGES



A NEW SCHOOL OF LEARNING

Cognitive impairment is common among childhood cancer survivors. Over 50% of teens and young adult survivors experience some form of learning problem, which can appear over time. Yet not all survivors are aware that their cancer has affected their ability to learn. Maintaining good grades in high school doesn't necessarily mean that your ability to learn has not been affected by your cancer treatment.

Cancer treatment interferes with the growth of the brain. You may not detect a disability until a new skill is needed and your brain has not reached the stage of growth required to complete it. Not all survivors experience learning problems, but it's important to educate yourself on the potential challenges that may affect your ability to get the most from your education.

COMMON LEARNING PROBLEMS

There are often problems that arise in a young cancer survivor's ability to learn. These include:

- Fatigue
- Declines in intellectual ability over time
- Problems keeping up in social conversations and in detecting social cues
- Inability to sustain attention or avoid "spacing out"
- Difficulty remembering information that is seen, as opposed to heard
- Trouble comprehending material that is read visually (although reading the words often isn't a problem)
- Difficulty writing by hand quickly or accurately
- Inability to copy or write information that is seen
- Trouble completing tasks quickly
- Difficulty keeping pace with new material
- Problems retrieving information that is novel or that doesn't have meaningful context
- Trouble performing math calculations such as multiplication or division
- Difficulty planning and staying organized
- Remembering sequences of information

ALL IS NOT FORGOTTEN

While treatments can take their toll on your learning, not all areas of the brain are affected by your medical history. Survivors often can learn and remember information that is heard. Many can understand the application of math concepts and learn by using spoken language to communicate new material. If given enough time, most survivors can recall information accurately and have no trouble tapping into their creativity.

EDUCATIONAL CHALLENGES



LEARNING TO LEARN AGAIN

There may come a time when you realize that you need to adjust the way you learn. It doesn't mean that you aren't as intelligent as you once were or that cancer has left you incapable of learning. It merely means you will need to explore other study methods in order to succeed.

Chances are, you have already incorporated new methods into your studies. If you were diagnosed in high school, you are probably actively involved in obtaining the necessary support. Success in school with a disability involves knowing your disability, being able to communicate with others about it, and being your own advocate to ensure you receive the accommodations necessary to get the most out of your educational environment.

BE YOUR OWN BIGGEST SUPPORTER

As a cancer survivor, advocating for yourself is critical. High school is a great time to begin acting as a "champion" for your own educational needs. Above all, learn how to describe your disability, your history of learning problems and the way the problems present themselves. Be able to communicate the type of setting that is most conducive to learning and be flexible with finding tools to create that environment. Auditory learners, for example, can bring a tape recorder to lectures in order to listen to the information several times. Identify your own strengths and vulnerabilities and try to accommodate them.

Practice discussing your disability with someone such as a guidance counselor. Learning how to communicate this information will prepare you for the college admissions counselor and prospective employers.

If you have a learning disability, it will always be a part of your life. It may be difficult to accept your new normal. But if you understand your own strengths and weaknesses and learn to advocate for yourself, it will help you throughout your life's endeavors. With time, you'll learn that everyone has differences and it helps to talk honestly about your own challenges.

YOUR LEGAL RIGHTS

Some of the laws governing elementary and secondary education don't apply to higher education. However, under both ADA and Section 504 of the 1973 Rehabilitation Act, colleges and universities that receive federal money are required to provide reasonable modifications, accommodations, or auxiliary aids that will enable qualified students to have access to, participate in, and benefit from the full range of the educational programs and activities offered to all students on campus. These laws also apply to admission testing. You should be familiar with the following laws and understand how they apply to you.

The Rehabilitation Act of 1973. Section 504. If you have a physical or mental impairment (a cancer diagnosis is considered "other health impaired") that substantially limits a major life activity, Section 504 upholds your rights to equal access to educational services. This is true for any college or university that receives federal money. To learn more, visit the Department of Labor's 504 website at dol.gov.

EDUCATIONAL CHALLENGES



Americans with Disabilities Act (ADA) of 1990. This act guarantees the civil rights of persons with disabilities. Learn more on the ADA homepage at ada.gov.

Individuals with Disabilities Act (IDEA). This act guarantees a free and appropriate public education and governs the provision of special educational services to students with disabilities.

Family Education Rights and Privacy Act (FERPA). Passed in 1974, this act ensures that written records will be confidential and available only to those with a legitimate interest in them. These records cannot be shared without the student's permission.

KEEP RECORDS THAT MAKE THE GRADE

It's never too early to start keeping accurate and up-to-date educational records. This will help you as you begin preparing for college admission. Your educational records should include this information:

Contact information- Include information about the schools you attended, teachers' names, correspondence from the school, all test results, report cards, IEP's and ITP's.

General health information- Immunizations, medications, attendance records and correspondence to and from the school about your treatment should be accurately entailed.

Special requests- If you have made any special requests from the school concerning your health or learning, document them and keep them with your academic files.

THINK THROUGH YOUR COLLEGE DECISION

Choosing a college is a big decision for anyone. But when you are facing learning challenges, the decision entails more thinking and planning. When you're ready to start the college search, make a list of questions and requirements that you have for the school. Consider your comfort level in describing your disability and in advocating for your own needs. This may influence your choice. Figure out what accommodations you require and compare them to the services and support that are already in place at the school. Think about location and the reputation of the educational program.

Here are some good questions to ask:

- Does the school have an office that serves students with disabilities, including a full-time staff (Student Disability Service, SDS)?
- How long has the program been running?
- What type of support does the SDS office offer?
- Are the counselors or staff specially trained in working with learning disabilities?
- Is there any threat that the office will close before you finish college?
- Do they have an ADA/504 coordinator?
- Who can your parents contact if they have questions during the school year?
- Who counsels students during registration, orientation and course selection?
- Is tutoring available? Are the tutors professors or students?
- Is tutoring automatic or will you have to request it?
- Does the college have an established grievance policy?
- Has it published a notice of nondiscrimination?
- Does the college faculty receive any disability awareness training?
- How do you request classroom accommodations?
- Does the college offer early enrollment to give you time to meet with professors and learn where your classes are?
- Can you take longer to graduate?

EDUCATIONAL CHALLENGES



FINDING FINANCIAL AID

The federal government offers financial aid packages to help families meet educational expenses. The majority of financial aid programs are based on the needs of the student and typically require/expect some financial support from the parents.

In order to receive financial aid, you must complete a Free Application for Federal Student Aid (FAFSA) form. You can usually get these through your high school guidance counselor. You'll also find them online at fafsa.ed.gov or by calling 800-4FEDAID. You must fill out these forms early and with accuracy. If you have a learning disability, your vocational rehabilitation counselor or your social security case manager can help you apply for financial aid.

These applications require families to estimate their expenses. Under certain circumstances, costs related to a student's disability may be included in the total. Items that may be included:

- 1) **Special equipment and its maintenance.** Some of this equipment may have been covered by your high school, but in college, it will be your responsibility. These include things like batteries for hearing aids or an adapted computer.
- 2) **Services for personal use or study.** These may include readers, interpreters, note takers or personal care attendants.
- 3) **Transportation.** If traditional transportation isn't accessible, this may be covered.
- 4) **Medical expenses.** Those expenses not covered by insurance may be covered if they relate directly to your disability.

If any of your expenses are covered by insurance or any other agencies, you must also list those for accuracy.

HELP FOR THOSE WHO SEEK IT

Survivors may also receive assistance under Social Security Income or Social Security Disability Insurance. Most states also offer some sort of student assistance. To find out what is available in your state, ask your guidance counselor. There are scholarships specifically available for childhood cancer survivors. The NCCS Beyond the Cure Ambassador Scholarship Program offers college and vocational scholarships each January for the subsequent academic year. Once the program opens each year, the application is available on the NCCS website at theNCCS.org. You'll also find a list of additional scholarships under "Helpful Links".

AID THROUGH VOCATIONAL REHABILITATION

Generally, state vocational rehabilitation offices (VR) are designed to help get people employed, but they are also essential in the college process. If you qualify for vocational rehabilitation, your VR counselor can review your educational plans in terms of job potential. This will help guarantee that the field you are choosing is a match for your talents and strengths and that employment opportunities will be available to you.

Under the Rehabilitation Act, if you qualify for vocational rehabilitation, you must apply for financial aid. Applications are available at fafsa.ed.gov. Because you must work with both the college's financial aid and VR offices, this can be a lengthy and time-consuming process. Contact both offices early in your college application process or while you are still in high school.

EDUCATIONAL CHALLENGES



In the employment section of this guide, you'll find additional information on qualifying for vocational rehabilitation. Some VR services, such as college, are based upon financial need. They also ask that you provide documentation of your income. Individuals under 23 years of age who are still living at home will be required to provide proof of their parents' household income.

Depending on your financial and learning needs, VR may provide funding or other assistance to help with:

- Tuition expenses
- Transportation/commuting expenses
- Books and supplies
- Read/note-taker services for people who are blind or have learning disabilities; interpreter services for people who are hearing impaired; and/or individually prescribed aids and devices
- Telecommunications, sensory and other technological aids and devices
- Other goods and services that help an individual with a disability become employed



"The hardest part of dealing with these late effects is that people do not understand why you are struggling if you are not sick anymore. As survivors, we need support to know what to do next. We have to advocate for our rights in school."

Ashley, Leukemia Survivor

"The high-dose radiation that I received on my brain has given me short-term memory loss and other problems like persistent nausea that makes taking tests difficult."

Vince, Brain Cancer Survivor

EASE YOUR WAY IN

Once you decide which school to attend, it's time to focus on tuition, health insurance and adjusting to your new routine. These practical tips will make the transition to college a little easier.

- 1) **Be realistic about the graduation timeframe.** Think through your course requirements, course sizes, course waiver provisions and curriculums. Consider graduating in 5-6 years instead of feeling pressured to complete your education sooner.
- 2) **Choose teachers whose teaching style complements your learning style.** If you learn best by participating in class discussions, ask your peers or your advisor to help you choose professors who encourage this method of learning.
- 3) **Understand your health insurance.** Check with your parents and the college about coverage options. Know your provider and be familiar with the details of your plan.
- 4) **Get to know students with disabilities.** If you are comfortable, they can provide guidance dealing with the kinds of problems you may face.
- 5) **Manage your time well.** Even if you have done well in high school, understand that college will be challenging. Know your limitations and discuss any problems you are having with a teacher, advisor or your parents.

WORK AND EMPLOYMENT



GAINING INDEPENDENCE AND FINANCIAL SECURITY

Being employed is an important part of life. In your teen and young adult years, taking on a job can give you a sense of belonging, boost your self-esteem and provide mental stimulation. All of these can be rewarding. But as you reach adulthood, employment takes on even greater significance because for many people, work is their only source of financial security and health insurance.

Choosing a work path requires a lot of thought. As a survivor, you will need to consider whether your physical and emotional health are suited to the kind of work that you have chosen. If you have concerns, talk to your healthcare team. They can help you set realistic expectations for yourself and alleviate your anxieties. Unless you have specific physical or mental limitations that affect the type of work you are going to do, your cancer history shouldn't affect your ability to get a job. By law, an employer cannot refuse to hire you simply because you are a cancer survivor.

That said, you may face challenges in the job market. Don't be afraid to seek help. Contact your hospital social worker, a job counselor or a state agency. You can also reach out to cancer support groups, your teachers or a career counselor at a local college. These people can offer you support, provide references and potential employment opportunities.

KNOW YOUR EMPLOYMENT RIGHTS

If you are qualified for a job, state and federal laws prohibit employers from treating you differently because of your medical history. It's important that you understand the provisions of your state's employment and discrimination laws. You can contact the Equal Employment Opportunity Commission at eeoc.gov or 800-669-4000 (voice); 800-669-6820 (TTY).

THE AMERICAN DISABILITIES ACT (ADA)

This federal and civil rights law, in part, prohibits discrimination in all employment practices. The act applies to companies with 15 or more employees. It pertains to job application, hiring, firing, advancement, compensation, training and other privileges of employment.

A cancer diagnosis alone isn't considered a disability. Each cancer case is evaluated on an individual basis. The ADA does not require that a person with a disability be hired over another qualified candidate. You must be qualified to perform the essential functions or duties of a job in order to be protected from job discrimination by the ADA.

These protections are offered by the ADA:

- 1) **Employers must ask only job-related questions.** It is illegal for a potential employer to ask about your medical history, including asking if you had cancer. An employer cannot request medical records from your doctor before making a job offer. If all employees are required to have a medical examination, you cannot be exempt. However, the medical examination must be related to the job and consistent with the employer's business needs.
- 2) **Employers cannot question your disability.** A potential employer cannot ask job applicants if they are disabled or question the nature or severity of their disability. They can however ask about your ability to do tasks related to doing a job.

WORK AND EMPLOYMENT



- 3) **Employers must make “reasonable accommodations” in the workplace.** An employer must make accommodations for a qualified disabled employee, at no cost to that employee. This includes making non-work areas accessible, but doesn’t include any form of personal aide such as hearing aids. Your potential employer may ask you to describe or demonstrate how you would be able to perform job tasks with or without reasonable accommodations made.
- 4) **Employers must treat all employees equally.** They cannot discriminate against an ill employee or a person whose family member is ill.

To learn more about ADA, call 800-514-0301 (voice) or 800-514-0383 (TTY). Services are also available in Spanish through the Department of Justice’s ADA website at [justice.gov](https://www.justice.gov).

THE EQUAL EMPLOYMENT OPPORTUNITY COMMISSION (EEOC)

The employment section of ADA is enforced by The Equal Employment Opportunity Commission. The EEOC provides information about your rights under ADA and explains ways to file job discrimination complaints. You can learn more on their website at [eeoc.gov](https://www.eeoc.gov). To speak to an EEOC representative, call 800-669-4000 (voice) or 800-669-6820 (TTY). If you believe that your rights under ADA have been violated, it’s your responsibility to speak up.

Keep these facts in mind if you’re considering filing a grievance:

- 1) **Discrimination suits are time sensitive.** They must occur within a specific period of time after the alleged complaint. In some states, it is up to 300 days. Check with your local field office for the requirement in your jurisdiction or call 800-669-4000.
- 2) **If the EEOC does not pursue your suit, you can request a “right to sue.”** You will have 90 days from the receipt of your EEOC letter to pursue further legal action.
- 3) **Grievances are time consuming and emotionally exhausting.** You should consider the long-term outcome you want and weigh the costs versus potential benefits of a grievance.
- 4) **Keep detailed records of your complaints.** These should include time, date and witness names.
- 5) **The Rehabilitation Act sets standards against discrimination.** It prohibits discrimination for a disability in programs conducted by federal agencies, programs receiving federal financial assistance, for federal employees and federal contractors’ employment practices. Standards are the same as those under ADA.
- 6) **FMLA makes provisions for family-related medical reasons.** The Family Medical Leave Act requires businesses with 50+ employees to give employees up to 12 weeks unpaid leave in a 12-month period for specified family and/or medical reasons. The employer must continue benefits and offer the same job or a lateral move upon return. FMLA is enforced by the US Department of Labor’s Wage and Hour Division [dol.gov](https://www.dol.gov).

EDUCATION HEALS IGNORANCE

Cancer no longer has the same stigma it carried 20 years ago, but there are still some myths surrounding a cancer diagnosis. Employers and coworkers who know about your health history may think that your past diagnosis still affects you today. They may worry that you’ll have further health problems which will saddle them with more work. They may unknowingly discriminate against you strictly out of ignorance.

Most of the time, these worries will pass if you can educate coworkers. By providing solid information about childhood cancer, you can dispel any fears they may have. Talk directly to those you work with and offer written information from a reliable non-profit such as The National Children’s Cancer Society. Work with your human resources director to arrange for outside speakers to further their education. However, if you continue to feel discrimination, contact the EEOC at [eeoc.gov](https://www.eeoc.gov) or 800-669-4000 (voice); 800-669-6820 (TTY).

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VOCATIONAL REHABILITATION (VR)

Every state offers vocational rehabilitation (VR) services for disabled individuals. Originally, these programs were developed for the deaf, the visually impaired, those with prosthetics or war veterans. Services have since been expanded to include a large group. The structure and location of the program varies from state to state, but all have the same fundamental purpose and goal: to provide comprehensive employment services to people with disabilities.

A cancer diagnosis alone isn't necessarily a disability. To qualify for services, you must document that you have a disabling condition that limits your ability to function in your job. Whether it is a physical, emotional or mental condition, you must prove that it interferes with your ability to obtain or maintain employment. Anyone over 16 can apply for VR services and there is no upper age limit. VR employers may not be aware of the late effects of childhood cancer, especially those related to learning disabilities. You may need to provide documentation from your healthcare team or educational testing that correlates with your late effects. If you are found ineligible, you can apply again if a new late effect appears.

I can
totally
relate.

Straight talk from other Survivors

"I want people to see me as hard-working and diligent, not someone who makes excuses. Plus, the problems that I deal with are things that are foreign to the general population. No matter what, though, I always let my employer know my limits. Some days are worse than others and having my boss understand why can make all the difference."

Casey, Ewing's Sarcoma Survivor

"Know your resume! Don't keep saying the same things, but rather use your resume as an outline in the interview and build off of it. It's your job to make the words jump off the page, so to speak."

Phillip, Ewing's Sarcoma Survivor

ADVOCATING FOR YOU

If you'd like to meet with a trained VR counselor, go online and find your local VR office. The counselor will determine your eligibility, provide vocational guidance and counseling and serve as your advocate. If you are found eligible, your counselor will work with you to develop a written, individualized rehabilitation plan to determine which services are required to help you become employed.

The cost of vocational rehabilitation will depend on your income and resources. The plan may include many things such as an assessment to determine employability, guidance in choosing an appropriate employment goal, counseling, physical and mental restoration services, assistive devices and vocational training. The vocational training may include tuition/fees, books, college materials, community rehabilitation programs, transportation and job-related tools/licenses and on-the-job training and other services leading to eventual employment.

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The employment goal must be shared by you and the rehabilitation counselor. You have the right to appeal at any time if you don't agree with the decision made by your counselor. You can appeal to the VR District Office supervisor, request mediation or request a formal review from Client Assistance.

You'll find additional VR information for secondary education in the "Educational Challenges" section of this guide. For your state's VR services, visit csavr.org. Be aware, some states call their vocational rehabilitation offices by a different name, such as Division of Vocational Rehabilitation and Employment or Office of Vocational Rehabilitation.

INTERVIEWING FOR JOBS

When you get ready to begin interviews, it can be a little scary. Keep in mind, the keys to successful interviews are preparation and honesty. Be sure your resume is accurate and that you are qualified for the job in question. Be truthful. If you are found to have lied on your application or during your interview, the employer has the right to fire you.

Here are some tips to make the job interview process go smoothly:

- 1) **Don't volunteer information about your health history.** An employer only has the right to know if you can perform the essential duties of the job. He/she does not have the right to ask about personal or confidential information, such as your cancer diagnosis, during an interview.
- 2) **Be truthful on your insurance applications.** Never lie about your cancer history. If you do, an insurance company may refuse to pay your benefits or cancel your policy. If asked an illegal question, answer honestly about your current abilities. Don't discuss your cancer history.
- 3) **Focus on your strengths.** Always push the things you do well. If asked, be honest about any gaps in your employment history. Potential employers may ask why you were out of work for a period of time. It's best to explain your treatment but focus on your current state of health.
- 4) **Practice interviewing.** Ask a job counselor, social worker or someone in a cancer support group to practice your interviewing skills. Focus on questions that make you uncomfortable.
- 5) **Don't ask about benefits in your initial interview.** Be sure to review the package before you accept a job.
- 6) **Stay informed about your legal rights.**
- 7) **Contact other survivors for suggestions.** Go to an online chat or a local support group for employment and interviewing tips.
- 8) **Organize your resume around your strengths.** It doesn't have to be done chronologically.
- 9) **Discuss potential roadblocks with an employer upfront.** If you will need reasonable accommodations to perform a job, discuss the issue with your employer.

As a survivor, seeking employment has its own set of challenges. You may want to consider starting your career with a big company. Typically, large organizations present many opportunities with fewer barriers to health insurance.



FINDING MEANING IN THE JOURNEY

You have your own, unique sense of spirituality - it's what gives all of the wonders and all of the suffering of life meaning. Spirituality is a journey-a state of experience and discovery. It does not have a fixed beginning or end. The spiritual part of who we are is where we make our connections and where we find life's meaning. This is especially true in the midst of those experiences that seem meaningless, difficult or unfair.

Spirituality and religion are not interchangeable. Although for some people, they may be interwoven and thereby inseparable as they complement each other. All human beings have an innate spirituality, but not all have a defined religion. Spirituality is at the core of what we believe and trust. Religion is often, but not always, the framework that makes spirituality work for us personally.

THERE IS NO WRONG RESPONSE TO CANCER

Cancer, and life after cancer, may lead to a spiritual struggle. You may question your relationship with others, the world and even your higher power. When a crisis occurs, many people immediately turn to their higher power for strength and answers, while others may push away.

Feelings of loneliness or isolation are common. You may feel as if you've been abandoned or separated from your former beliefs. Unless you confront this sense of isolation, it can be ongoing and damaging.

Anger is also a very common response. Anger is normal, especially under the stress and fear of a disease such as cancer. It is common to have these feelings and everyone experiences them differently and at different times. If you find yourself overwhelmed, reach out to a trusted family member, friend, spiritual advisor or professional.

FINDING SPIRITUAL SUPPORT

For many people, faith provides a sense of community. This community can be a source of strength and support during and after cancer. Within your community, you can receive care that may provide you with healing, guidance and support.

Spiritual matters call for spiritual caregivers who can provide support throughout your cancer experience and beyond. This caregiver can be a clergy person from your faith community, a hospital chaplain, a good friend, a family member or other spiritual guide. Whoever you turn to, be sure they:

- Listen well
- Accept your own spiritual journey
- Be open to understanding your spirituality and faith
- Allow for questions without always providing answers
- If needed, act as a liaison with your faith community
- Be open to expressed hopes and concerns
- Be comfortable discussing spirituality, faith and religious issues



TREATMENT ENDS, SPIRITUAL EVOLUTION FOLLOWS

After months or years of treatment, you are bound to experience physical, emotional and spiritual change. If during your treatment, spirituality took on an important and positive role, it will likely continue to be something you embrace and nurture. However, if you did not find a spiritual dynamic during treatment, you may wish to explore this further. Exploring your own spirituality may give you access to new support and help you find some kind of understanding and peace about your cancer and the treatments you endured.

Intense emotions may still follow you. Anger or other strong feelings may resurface as a late effect. Life may not be what you had planned and you may face constant reminders of your cancer. Some survivors direct this anger or resentment at the people they are closest to. Other times, it may be directed at your spiritual being.

Anger is normal, but you can control how you express your feelings. By accessing your spiritual side, you will find tools to cope with the emotions that your cancer struggle has caused you. Learning ways to normalize these intense feelings allows you to create a safe place where you can feel at ease in engaging in spirituality or faith.



"Life is hard, fun, sad and very unpredictable, but I believe cancer has given me the drive to fight and succeed. It makes me expect the unexpected and it reminds me to thank God for every good day because I know what a bad day is really all about."

Mary, Leukemia Survivor

"During treatment, I found problems with God, but I realized I was looking at the situation wrong. I started focusing on what was beneficial from my treatment and it helped me remember that God always has a plan for us. I just needed to embrace that plan."

Maggie, Lymphoma Survivor

A NEW JOURNEY BEGINS

Everyone has their own unique sense of spirituality that gives their life meaning. As you continue on your own spiritual journey, reach out to family or friends. If you find those closest to you are not the best source of spiritual support, talk to a member of the clergy or a fellow survivor. Find the support you need and communicate openly.

Think of spirituality as another late effect of cancer and find new ways of dealing with it. Here are some tips.

- 1) **Be open to the breadth and depth of yourself.** You have the reserves within you to sustain yourself through many difficulties.
- 2) **Embrace your strength of spirit.** This is what has maintained you thus far and gotten you through your illness.
- 3) **Speak for yourself.** No one understands your spiritual journey better than you.

Be kind to yourself, reach out to others and remember you are not alone.

Content contributed by Rev. Dr. Jay Kanerva, Spiritual Care Coordinator at Ranken Jordan Pediatric Bridge Hospital



MOVING FORWARD BY GIVING BACK

As a cancer survivor, you've faced many serious life challenges. The success you've had in conquering them can make you feel powerful, hopeful and determined. So much so, that you may find yourself eager to help other cancer patients.

Many cancer survivors learn to advocate on behalf of other cancer patients and survivors. By sharing your experience with professionals, politicians and the general public, you raise awareness of childhood cancer and advance the causes related to it. As an advocate, you have the potential to effect individual, institutional or social change. Being part of the solution can help you make sense of your health history and help you move forward.

BE YOUR OWN BIGGEST SUPPORTER

Without a doubt, as a childhood cancer survivor you will need to learn to advocate for yourself. Surviving cancer impacts so many areas of your life. You will need a strong support system, as well as a medical network to monitor late effects and obtain the appropriate follow-up care. You, in a sense, will need to find your place in the cancer community.

How can you advocate for yourself?

- 1) **Talk about your cancer experience.** Share your feelings with friends and family.
- 2) **Consider a support group.** Join, or even start a group in your community or hospital.
- 3) **Create your own network.** Fill it with people who are experts in the areas important to cancer patients, such as educators, insurance specialists, legal experts, doctors and social workers.
- 4) **Attend a survivor's camp.** Go to a young adult survivor's camp or become a counselor at a camp for children with cancer.

Your experience as a childhood cancer survivor has given you rare insight into the changes that need to be made within the community to accommodate children with cancer. Hospital policies may need to be changed, schools may need to be educated about the late effects of treatment and employers need to be more aware of the special issues survivors face. As a survivor, you have the inside knowledge to be an effective part of the solution.

YOUR ROLE IN THE COMMUNITY

Making the commitment to take an active role within the community is an admirable act. Here are some ways you can get involved:

- 1) **Contact a local children's hospital.** Be an advocate for a newly diagnosed child.
- 2) **Get involved.** Try to influence current hospital policies if you believe they can be improved.
- 3) **Talk about your cancer.** Go to a local civic group and share your experiences.
- 4) **Become a charitable fundraiser.** Raise money for a charity that supports childhood cancer issues.
Or step up by making a donation. The NCCS helps childhood cancer patients and their families through a variety of programs.



- 5) **Contact nonprofits or survivorship clinics.** Look for opportunities to volunteer and share your experience.
- 6) **Educate the faculty at your school or college.** Educate them on the long-term issues survivors face.
- 7) **Explore the resources available for survivors on college campuses.** Advocate for any needed accommodations.



"I have made lifelong friends at the camps I have attended. I had the opportunity to volunteer as a camp counselor last year and hope to be asked to return again this year. I strive to give these kids a good time, just as my counselor gave me and it makes me feel good to give back."

Mary, Leukemia Survivor

"As a survivor, I feel a strong need to give back and use my knowledge and experiences to help others. It's an important part of survivorship which has helped me find meaning and make sense of my life."

Jenna, Lymphoma Survivor

CHANGES ON A LEGISLATIVE LEVEL

Legislation has a big impact on the lives of cancer survivors. You have the opportunity to use your voice to influence policies and budgets that will affect all survivors. There are opportunities for change on both the national and the local levels. Here are some places to start.

- 1) **Know your elected government officials and how to contact them.** Visit senate.gov or house.gov to reach the officials from your state. You can also find your state's website by typing www.<your state's abbreviation>.gov.
- 2) **Become familiar with the federal and state laws that affect you.** Cancer advocacy organizations such as Children's Cancer Cause (childrenscause.org) and the National Coalition for Cancer Survivorship (canceradvocacy.org) will help you stay up on laws that affect the survivorship community.
- 3) **Join an advocacy group.**
- 4) **Talk to people around you about the issues that are important to survivors.** With so many issues fighting for public attention, many people aren't aware of the issues affecting cancer survivors.
- 5) **Reach out to the community.** Communicate about budget and legislative issues that matter to cancer survivors. Call a radio station. Write a letter to the editor of a newspaper or magazine. Be proactive.
- 6) **Contact officials by phone, letter or email.** Share your personal history and voice your concerns. Always include your contact information.

Advocacy can be challenging and frustrating, but it can also be extremely rewarding. Whatever path of advocacy you choose to pursue, you are taking a step towards healing. You are making a difference in your own life and the lives of countless other survivors.

RESOURCES



Medical and Survivorship

Beyond the Cure Survivorship Program

sponsored by The National Children's Cancer Society

800-532-6459 theNCCS.org

Information on cancer survivorship, including a late effects assessment tool, college scholarships and an online community.

Children's Oncology Group

childrensoncologygroup.org

Contains survivorship guidelines and lists the hospitals which are members of the Clinical Oncology Group in the United States.

National Cancer Institute (NCI)

800-422-6237 cancer.gov

Information on the latest findings related to late effects of cancer treatment, clinical trials, cancer clusters, research, and statistics.

Fertility and Adoption

The Center for Young Women's Health-Children's Hospital

617-355-2994 youngwomenshealth.org

Addresses the impact cancer may have on hormones, ovaries, fertility, pregnancy and sexual relationships. Available in Spanish and English.

Livestrong

855-220-7777 livestrong.org

Information on infertility issues for cancer survivors. Compares various fertility options and has up to date information on pre and post-treatment choices.

Child Welfare League of America

202-688-4200 cwla.org

Resources for adoption and adoption funding on their website.

Health and Prevention

SmokeFree

877-448-7848 smokefree.gov

Help for those who want to quit smoking.

American Institute for Cancer Research

800-843-8114 aicr.org

Offers specific nutrition information for the cancer survivor.

Emotional Support

American Cancer Society

800-ACS-2345 cancer.org

An online community for adult and childhood survivors and their families with both chat and message board.

Stupid Cancer

877-735-4673 stupidcancer.org

Addresses young adult cancer through advocacy, research and support.

Cancer Support Community

888-793-WELL cancersupportcommunity.org

Professionally monitored online community for teens with cancer.

Health Insurance

HealthCare.gov

healthcare.gov

800-318-2596

A government sponsored website on healthcare information.

Patient Advocate Foundation

800-532-5274 patientadvocate.org

Provides assistance with insurance problems, and works to resolve coverage and benefit issues.

Social Security Administration

800-772-1213 ssa.gov

Provides answers to questions regarding social security benefits.

Scholarships and Education

Beyond the Cure Ambassador Scholarship Program

800-532-6459 theNCCS.org

Awards college scholarships to childhood cancer survivors.

Scholarships for Survivors of Childhood Cancer

ped-onc.org/scholarships

Provides list of scholarships for survivors throughout the United States.

National Center for Learning Disabilities

888-575-7373 nclld.org

Solutions and opportunities for individuals with learning disabilities.

Employment

Americans with Disabilities Act (ADA)

800-514-0301 ada.gov

ADA regulations, information and enforcement.

Department of Labor/FMLA

866-4-USA-DOL dol.gov

Information about the Family and Medical Leave Act and federal employment laws.

Equal Employment Opportunities Commission

800-669-4000 eeoc.gov

Information about EEO Laws, how to file a discrimination charge and statistical information.

Advocacy and Camps/Retreats

Children's Cancer Cause

202-552-7392 childrencancer.org

Brings the voice of childhood cancer survivors and their families to national policies which will affect them. Provides updates on relevant policies and issues.

The Lance Armstrong Foundation

livestrong.org

Provides links to Capitol Hill and other advocacy efforts.

Children's Oncology Camping

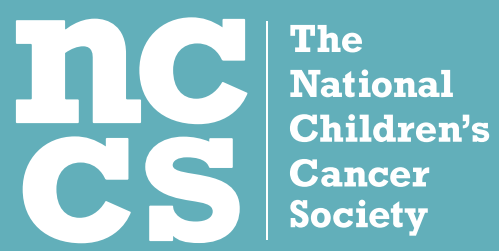
Association, International cocai.org

Connects children and families touched by childhood cancer to appropriate summer camps.

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